EXPLORARY STUDY: THE LIVED EXPERIENCES OF CAREGIVERS OF INDIVIDUALS DAIGNOSED WITH SCHIZOPHRENIA IN WINDHOEK, NAMIBIA

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EXPLORATORY STUDY: THE LIVED EXPERIENCES OF CAREGIVERS OF INDIVIDUALS DIAGNOSED WITH SCHIZOPHRENIA IN WINDHOEK, NAMIBIA

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ABSTRACT

The objective of this research was to explore the lived experiences of caregivers of people diagnosed with schizophrenia to understand the dynamics within these specific family settings. A qualitative approach with a systems theory lens was applied. A purposive sampling method was utilised to select a sample size of eight participants from the Windhoek Central Hospital’s Mental Health Unit, and face-to-face in-depth interviews were conducted with the individuals who met the criteria. Furthermore, thematic analysis was applied to identify prominent themes in the data. Key findings of the study suggested that there was a lack of communication between mental health workers and caregivers; information and knowledge on schizophrenia was not disseminated to caregivers. Additionally, the caregivers experienced financial and social burden in their caregiving roles, which was further exacerbated by inadequate social support that exist at a broader level. The study recommended that mental health workers take a proactive inclusive approach in educating the caregivers and their relatives with schizophrenia about the diagnosis, treatment and care of the illness. Furthermore, a need for additional services, such as community-based mental health centres for accessibility, support groups, as well as financial aid was identified to improve the quality of life of the caregivers.

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LIST OF ABBREVIATIONS

DSM	Diagnostic Statistical Manual of Mental Disorders
DJ	Disco Jockey
KZN	Kwa-Zulu Natal Province
MoHSS	Ministry of Health and Social Services
PAN	Psychology Association of Namibia
UK	United Kingdom
UN	United Nations
US	United States
WHO	World Health Organisation

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DEDICATION

This mini-thesis is dedicated to all the lay caregivers and relatives with mental illness. To the man with a mental health condition who use to sat at the corner of Fidel Castro and Mandume Ndemufayo Street and many like him. May we as humans, as we evolve, gain more awareness and compassion towards each other, more so, to those affected with mental illness.

"There's no health without mental health" Dr Brock Chisholm

DECLARATION

I, Justine /Oaes, hereby declare that this study is my own work and is a true reflection of my research, and that this work, or any part thereof has not been submitted for a degree at any other institution.

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CHAPTER 1

INTRODUCTION

1.0 Introduction

This chapter covers the background of the study, statement of the problem, the significance of the study, research questions and definitions of key concepts.

1.1 Background of the Study

Schizophrenia is a chronic, incurable mental illness which gradually impairs individuals' cognition (thinking), feelings and behaviour (Barlow & Durand, 2012). This condition inevitably affects the occupational and social functioning of such a person significantly (Barlow & Durand, 2012). There may be a reduction in the person's overall functioning and general effectiveness, including the workplace, and they may become socially withdrawn. Individuals who suffer from this illness may display psychotic (positive) symptoms, such as auditory (hearing voices) and/or visual hallucinations (seeing things) which are not real. The presence of delusions (false beliefs) is also predominant during the psychotic stage. The individuals tend to believe that they are some kind of an important or popular figure like a god or a president of a country. Additionally, these individuals are plagued by negative symptoms, which consist of reduced emotional expression, alogia (decline in speech) as well as avolition (the inability to engage in daily tasks such as bathing or brushing teeth) (Barlow & Durand, 2012).

Usually, the positive symptoms are dominant during the onset (beginning) phase of the illness, which indicates that the person's behaviour, thoughts and beliefs are not in line with what is considered to be socially or culturally acceptable or appropriate. In this thesis, the focus is on the caregivers of ill relatives who are on medication; their symptoms are therefore manageable. However, being on treatment does not offer immunity against relapse episodes as schizophrenia's causality is complex and multidimensional. One of the key causes or triggers for schizophrenia is chemical imbalance in the brain and this imbalance can be triggered by a variety of factors such as substance use and psychological stressors. Unfortunately, people diagnosed with schizophrenia are often known to have a high tendency for non-adherence to medication. An Indian study found that about 34% to 73% of schizophrenia patients are likely to default on medication (Patel et al., 2014), which is one of the most significant reasons for the poor prognoses. This inadvertently limits their ability to function independently in daily life, thus increasing their dependency on family caregivers and health workers.

For a clinical diagnosis to be made, individuals need to at least have two or more of the symptoms for a period of one month. It is a requirement that the diagnosis is made by a qualified clinical psychologist or psychiatrist. A *Diagnostic and Statistical Manual of Mental Disorder, fifth edition* (*DSM-5*) should be used as a guide (APA, 2013). In the case of the biomedical model of treatment, once the diagnosis is made and confirmed, the psychiatrist prescribes psychotropic medication such as Haloperidol, Fluanxol, Clopixol or Risperidone. These medications are administered either through ingestion or injection based on the condition of the patient (Patel et al., 2014). When the treatment is on out-patient basis, the patients and the caregivers are advised to return for follow-up visits for the evaluation of the patient’s progress. The medication is adjusted based on the evaluation of the follow-up if need to be.

The etiology (cause) of mental illnesses is generally complex, more so when it relates to schizophrenia. Numerous studies indicate that there is no single cause for schizophrenia. Amongst the causes and contributing factors are genetics, chemical imbalance, prenatal and perinatal influences, as well as psychological and social stressors (Barlow & Durand, 2012). Several genetic studies, including adoption and twin studies, postulate that the illness is largely hereditary and that children born to parents with schizophrenia are predisposed to the pathogenic gene. The studies further found that raising the offspring of biological parents with schizophrenia in a different environment does not exempt the children from carrying the potentially impairing gene, although it may delay the onset of the illness. However, a nurturing environment may lessen the chance of getting the illness for such children (Barlow & Durand, 2012).

From the chemical imbalance perspective, excess of dopamine (neurotransmitter) in the brain has been identified as the causal factor for the illness. The antipsychotic treatments used to reduce the positive symptoms in schizophrenia (caused by excessive dopamine) act by reducing the absorption of dopamine in the brain. It has been found that attempts to increase the dopamine levels in the brain through the use of anti-Parkinson disease (caused by a lack of dopamine) drugs often result in increased risk of triggering symptoms of schizophrenia (Barlow & Durand, 2012). This is indicative of the complex and multifaceted physiological nature of the illness. Hence, investigations are still ongoing to help individuals manage symptoms with the hope to enhance their overall functioning as there is yet no cure for the illness. A combination of several treatment approaches such as psychotropic drugs, psychotherapy and conducive social conditions, such as supportive home environment have been found to help manage the illness (Ganguly et al., 2018).

Maiocco et al. (2017) state that schizophrenia is one of the main causes of mental disability worldwide, as it places a heavy economic and psychological burden – cause other mental illnesses, such as anxiety and depression which can be burdensome to the broader society, including the caregivers and patients. Annually between $32 and $65 billion is spent on treatment and other financial expenses for schizophrenia globally (Maiocco et al., 2017). Although the illness does not discriminate along the lines of socioeconomic status, race or ethnicity, it seems to be more prevalent among men compared to women. Statistics indicate that schizophrenia affects more than 21 million people worldwide, of which 12 million are men, and that the average age onset is 21 years for men and 27 years for women (Maiocco et al., 2017).

As a standard procedure, generally, people with mental illnesses, more so with schizophrenia are institutionalised in psychiatric hospitals. That is, because, erratic behaviour such as aggression is predominant among some individuals diagnosed with schizophrenia, particularly, during an acute phase, which is difficult for caregivers to manage (Evans, 2009). Hence, a psychiatric hospital setting is important to foster the process of evaluation and effective care. However, the early 1950s and 1960s deinstitutionalisation – the discharge of patients from hospital care into community care – was introduced (Kamal, 2014). According to the latter scholar, deinstitutionalisation came about as part of the civil rights movement in the United States (US), which was against the lack of freedom of movement that people with mental illnesses endured. Furthermore, the deinstitutionalisation initiative became a capitalist movement because

Chlorpromazine, an antipsychotic drug, improved the functioning of people treated with the drug. This medical improvement was used as a motivation to discharge more people into the society but also to highlight the notion that psychosocial support was instrumental to the well-being of the individuals (Kamal, 2014; O'Brien, 2005). As a result, more and more family members without any prior knowledge or training on the illness assumed the role of the caregivers. Evans (2009) argues that this paradigm shift of transferred responsibility of mentally ill people to caregivers, without holistic consideration of such family system dynamics, could be detrimental for both parties, as the caregivers are often unprepared to handle an incurable illness such as schizophrenia.

The family role theory as postulated by Caqueo-Urízar et al. (2017), indicates that individuals diagnosed with schizophrenia negatively impact the normal functioning of their household, as family members are impacted in one way or another, causing some caregivers to lose the ability to perform well in their various roles in life. For example, depending on the perspective, when children are caring for parents with schizophrenia, those children often have to embody several other roles such as cooking, overseeing of medication or accompanying parents to doctor’s appointments, forfeiting their original role of being a child. Various studies found that caregivers of individuals diagnosed with schizophrenia struggle to cope psychologically and expressed feelings of burden, additional to the financial and physical stressors (Evans, 2009; Kamal, 2014; O’Brien, 2005).

In support, Caqueo-Urízar et al. (2017) stressed that about one third of caregivers expressed significant burden and difficulties in coping with either their partner’s or children’s mental illness. The family members further expressed unpleasant feelings, immediately after the diagnosis of the loved ones as they try to deal with the diagnosis. This emotional turmoil could be attributed to the limited knowledge caregivers have about the diagnosis and treatment of the illness (Evans, 2009). According to Suryani (2015), mental health professionals lack the means to provide caregivers with the much needed information and psycho-education. To confirm, Caqueo-Urízar et al. (2017) states that while some caregivers report on warm and positive relationships with mental health professionals, others report on insufficient information and feeling dismissed. Lack of collaboration still seems to be an issue between caregivers and mental health professionals, despite significant evidence that caregivers' involvement has positive outcomes for persons with schizophrenia.

In conjunction with the burden and lack of knowledge on the subject, the caregivers also expressed concerns about the limited availability of community resources such as clinics and medication. According to Kamal (2014), deinstitutionalisation seems theoretically sound, but is not feasible in reality as many people with mental illnesses in the US do not either have medical aid services or have access to better drugs. This is despite the US having the highest deinstitutionalisation rate compared to other countries, as approximately 1.1% Americans; equivalent to 2.2 million above the age of 18 years are diagnosed with schizophrenia (Evans, 2009). The people mostly affected by the inconvenience of deinstitutionalisation, are those that comorbid with substance use disorder, forcing an already vulnerable population into criminal activities as they seek to maintain their substance dependencies, which ultimately puts additional stress on the caregivers. According to Goswami et al. (2004) self-medication – the use of substances among people with schizophrenia is common because certain substances, such as alcohol and cannabis are perceive to reduce certain psychiatric symptoms and emotional distress affiliated with the illness.

Within the African context, numerous studies conducted in developing countries such as Ghana, Nigeria, Zimbabwe and South Africa emphasised the burden on caregivers of schizophrenia. Although mental disorder burdens are globally estimated at 14%, the greatest burden is experienced within the developing countries (Ae-Ngibise et al., 2015). A study conducted in Nigeria found that extended family members in Africa are responsible for the majority of the social and economic support of people with mental illnesses ever since the community care psychiatry interventions have been introduced (Oshodi et al., 2012). This unexpected burden may be worrisome for some caregivers as many of them may be economically unstable to carry the responsibility.

In Zimbabwe specifically, with the introduction of deinstitutionalisation, access to mental health facilities has proven to be a challenge as community centres are unable to provide basic facilities such as hospital beds and staff (Marimbe-Dube, 2013). As a result, family members, especially, those located in rural settings are responsible for caring for their mentally ill relatives at home. According to Lippi (2016) and Monyaluoe et al. (2014), the global deinstitutionalisation policy has failed to put sufficient protective factors in place for the caregivers and the individuals with mental illnesses. The latter problem seems to be an issue in developing countries because of the lack of community care centres available due to financial constraints in these contexts (Lippi, 2016). Hence, governments globally are condemned for expecting ill-equipped family members to carry the burden of people with mental illnesses on a long term basis. Although there seems to be a shift in South Africa, as professionals within the mental health fraternity are breaking barriers by providing mobile community counselling services to the public (Visser & Moleko, 2012), as a continent, Africa still have a lot to attain.

Namibia is no different to the rest of the world as schizophrenia is considered to be one of the most common mental health disorders in the country (Dhaka et al., 2017). According to senior nurses, Nkolonga and Kazarako (personal communication March 19, 2019) from the Windhoek Central Hospital's Mental Health Unit, records indicate that schizophrenia ranks monthly among the top three mental illnesses, with case intakes varying between 224 and 337 per month. Also, *News24* (as cited in Dhaka et al., 2017) revealed that Namibia treated 8000 different mental illness cases in 2015. Unfortunately, there seems to be a great disparity between the population with mental illnesses and availability of resources.

An article published in *The Namibian* (Kangootui, 2018) reported that there was a shortage of psychotropic medication at the Windhoek Central Hospital, which resulted in many patients being turned away untreated. In addition to this, Dhaka et al. (2017) and WHO's prolife for countries (2011), identified only two state owned Mental Health Units in the entire country with 192 beds between the two hospitals; 112 beds at the Windhoek Central Hospital's Mental Health Unit and 80 beds at the Oshakati Psychiatry Ward, respectively. This finding highlights the country's mental health challenges and subsequently, magnifies the anticipated burden caregivers may experience, as the majority of individuals diagnosed with schizophrenia are likely to be in the care of their family members. This assumption is made based on the lack of resources available in the country compared with the cases reported. For example, lack of mental health professionals, medication and mental health units (Dhaka et al., 2017).

1.2 Statement of the Problem

Worldwide empirical studies found that between 30-85% of adults with schizophrenia are in the care of family members and that the probability of those living at home with chronic schizophrenia is between 50-90% (De Sousa et al., 2012; Riley-McHugh et al., 2016). Additional studies, using qualitative and quantitative approaches, conclude that burden and stress have risen among caregivers since the responsibility of the people with mental illnesses have been shifted to community care (Kamal, 2014). According to Riley-Mchugh et al. (2016), the majority of caregivers (as high as 90%) experience moderate to severe burden, with those caring for individuals diagnosed with schizophrenia specifically at a higher risk of developing mental disorders such as depression and anxiety compared to those caring for dementia patients. The above-mentioned statistics seem to support the WHO projection that in 2020 mental health is bound to be the greatest burden (Maiocco et al., 2017)

Not only is schizophrenia a common mental illness in Namibia, but the researcher could not establish a study that has been specifically conducted on the experiences of family caregivers of individuals diagnosed with schizophrenia in the country. This is despite the integral role that caregivers play in the well-being of their ill relatives' lives and support they give. Because of their caregiving role, family members are exposed to difficult experiences (Evans, 2009). The Kamal study (2014), which is the backdrop of this research, also identified the lack of empirical investigation into caregivers' perspective, and highlights the continuous minimising of caregivers' experiences despite the burden experienced by caregivers as a result of the ongoing deinstitutionalisation.

1.3 Research Questions

This study on Windhoek caregivers aims to address the following research questions:

1.3.1 How do caregivers understand schizophrenia and *make meaning* of it?

1.3.2 How do caregivers of individuals diagnosed with schizophrenia *experience* caregiving?

1.3.2 How do the caregivers *cope* with schizophrenia?

1.3.3 How do caregivers *experience the services* provided for people with schizophrenia?

1.4 Significance of the Study

This present study is relevant and essential for Namibia. Firstly, the government's Mental Health Unit is in a dire state, which inadvertently disrupts the effective care and support the caregivers could give to their relatives with schizophrenia. And therefore, fails to ease the burden experienced by caregivers and limits the quality of life of the caregivers, as well as those diagnosed with schizophrenia. Secondly, the current study will provide insight into the caregivers' personal experiences and the responsibilities attached to the role while simultaneously highlighting the needs and challenges of the caregivers. Previous studies conducted with this population identified community care-based facilities and family psycho-educational programs as interventions that have proven to help family members cope (De Sousa et al., 2012). Thirdly, the study could breach the existing gap between the caregivers and the mental health professionals. Bridging the gap is imperative because caregivers are the pillars of strength for their relatives who are diagnosed with schizophrenia and therefore, their well-being is essential. The working assumption of the present study is that when caregivers are informed or knowledgeable in the subject of schizophrenia, they are most likely to care better for their ill relatives and can benefit from a better quality of life. Numerous studies have indicated that when caregivers of people with schizophrenia are informed, knowledgeable in the subject and receive support from informal and formal systems, such as family and mental health professionals, that those in their care have better prognoses (Evans, 2009; Iseselo et al., 2016; Milliken, 2001). Lastly, the current study may serve as an entry point for new investigations into the family dynamics of people with mental illnesses, more so schizophrenia. It may also create more awareness of the importance of mental health in Namibia both for the public and stakeholders.

1.5 Definitions of Key Concepts

1.5.1 Lived Experiences

According to Given (2008), lived experiences in qualitative research is explored and understood as a depiction of the research participants’ (in this case the caregivers) human experiences, their choices and options and how these aspects inform their perceptions of knowledge. The experiences speak to the caregivers' personal accounts obtained through living with and caring for people with mental illnesses. For this present study, experiences will represent the family members’ versions of caring for people with schizophrenia and the impression left on them emotionally, socially or interpersonally (Nxumalo & Mchunu, 2017).

1.5.2 Caregivers/Family Members

For this study, the terms caregivers and family members will be used interchangeably when referring to family members that are responsible for caring for the people with schizophrenia. These caregivers or family members are either biologically or socially related to the people diagnosed with schizophrenia in the capacity of a sibling, parent or partner and has been living with the persons with schizophrenia for at least three consecutive months, which primarily qualifies them to give authentic accounts of their experiences (Nxumalo & Mchunu, 2017).

1.5.3 Mental Illness

Mental illness refers to a spectrum of cognitions (thoughts), emotions (feelings) and behaviours (actions) that affect a person's interpersonal relationships as well as their social and occupational functioning (Johnston as cited in Overton & Medina, 2008). Mental illness, also referred to as a mental disorder in this present study, consists of various disorders, such as depression, anxiety and many more illnesses that are diagnosed clinically using the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association [APA], 2013). However, for the purpose of this current study, mental illness will be used interchangeably when referring to individuals diagnosed with schizophrenia.

1.5.4 People, or Relatives or Individuals with Schizophrenia

The use of people or individuals or relatives with schizophrenia in this study refers to persons clinically diagnosed with schizophrenia using the *DSM* by a mental health professional such as a psychologist or psychiatrist (Nxumalo & Mchunu, 2017). The individuals are on medical treatment and in remission state.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

This chapter covers the review of previous literature that have investigated caring of schizophrenia patients and related shifting roles. The evolution and effects of deinstitutionalisation, burden of schizophrenia, psychological burden and physiological health of caregivers of schizophrenia patients, as well as everyday life challenges involved in the care role; such as financial burden associated with caregiving, loss of time, social isolation, care and support, caregiver needs and interventions, and the theoretical framework for the study are discussed in this chapter.

2.1 Shifting Roles of Caring for People with Schizophrenia

Numerous studies that have investigated families and schizophrenia found that family members have become primary caregivers of the individuals diagnosed with schizophrenia; a position which was previously occupied by governments worldwide (Kamal, 2014; Marimbe-Dube, 2013; Monyaluoe et al., 2014; O'Brien, 2005; Oshodi et al., 2012). Deinstitutionalisation of people with mental illnesses, especially those diagnosed with schizophrenia, is the main cause of the shift in responsibility of family caregivers (Kamal, 2014; O'Brien, 2005, Turner, 2004; Yohanna, 2013). As a result, newer studies are focusing the lens on the experiences of family caregivers of those diagnosed with schizophrenia. Trivedi (2002) confirms that this pattern has been evident over the past five decades because of the surge in the number of studies concentrating on the relationship between the families and schizophrenia.

2.2 The Evolution and Effects of Deinstitutionalisation

Deinstitutionalisation is the process of discharging patients from hospital care into community care (Kamal, 2014) which dates back as far as the 1950s. According to Shen and Snowden (2014), the *United Nations* (UN) and the WHO proposed for the release of people with mental illnesses from institutions into community care as part of a national health policy. This decision was firstly driven in the United States (US) by the civil rights movement in the 1950s which was against the inhumane and harsh circumstances people with mental illnesses endured in the mental hospitals (Kamal, 2014; O'Brien, 2005; Turner, 2004; Yohanna, 2013). Patients who were hospitalised on long term basis and those admitted involuntarily had limited freedom of movement. In retrospect, the civil rights initiative was meant to empower people with mental illnesses (Kamal, 2014).

Secondly, the deinstitutionalisation movement was seen as a cost cutting project (Yohanna, 2013). According to Yohanna (2013), the Medicaid system in the US partnered with the federal government and shared half the cost that transpired in the closing down of all state-owned psychiatric institutions. This saw the birth of privately managed alternative housing schemes for people with mental illnesses that predominantly benefitted the Medicaid, the state and those that ran the alternative housing (Kamal, 2014; Segal & Jacobs, 2013; Yohanna 2013). As a result, deinstitutionalisation was criticised for favouring only the middle-class people who had less severe mental illnesses, while the system subjected poor people, and those with severe mental conditions to insufficient services and limited time for community integration (Yohanna, 2013). Many people with mental illnesses, globally, were unable to integrate successfully into family settings or community care facilities, and therefore, found themselves in homeless centres or prisons

(Segal & Jacobs 2013; Yohanna, 2013). It is then arguable, that deinstitutionalisation was in fact at the expense of poor people with mental illnesses who are the majority, and their caregivers.

Similarly, European movements that rose during the 1960s and 1970s, such as the United Kingdom movement, known as the “anti-psychiatry” movement that was formed against the backdrop that psychiatric diagnosis was unreliable; as well as the Italian movement, known as the “abbandannoti” movement, viewed deinstitutionalisation as a capitalist ploy (Turner, 2004). Turner (2004) posits that people with mental illnesses were subjected to harsh practices and appalling conditions, such as overcrowded facilities with limited resources. This resulted in the “abbadonnoti” movement deserting all psychiatric hospitals and refusing readmission of patients, despite, the social challenges that were associated with the movement in certain parts of the country (Turner, 2004).

On the contrary, Yohanna (2013) argues that prior to the 1950s, the mental health institutions were historically known to provide good work environments besides the biomedical and psychotherapeutic interventions it offered. The study further states that people with mental illnesses had opportunities to engage in workshops and vocational trainings that equipped them with skills to either make or grow produce that benefitted them. These findings legitimised the argument that institutionalisation of people with schizophrenia was beneficial for the patients, even though there was a high relapse predisposition among these individuals (Johnston, 2013). Consequently, the high relapse rates were attributed to family members’ inability to provide healthy environments for those with schizophrenia. Mothers, in particular, were blamed for causing schizophrenia in their children as per the “schizophrenogenic mother” theory (Johnston, 2013). Frieda

Fromm-Reichmann, a psychiatrist who termed this theory in 1948, explained that schizophrenia symptoms resulted in children as a coping mechanism because of overprotective nature of mothers or mothers rejecting children during childhood.

Interestingly, the debate around the family members' relation with schizophrenia has been changing over the years as more positive narratives are reported. For starters, the "*schizophrenogenic mother*" theory was criticised for excluding other social processes such as churches, community members and teachers that are also contributing factors that shape children's personality and personhood when conceptualising schizophrenia (Kirby, as cited in Johnston, 2013). Hence, the "*schizophrenogenic mother*" or "*schizophrenogenic families*" theory holds no weight in this day and age. Furthermore, the psychosocial support provided by families towards people with schizophrenia helps in the reduction of the relapse rates (Trivedi, 2002). A study conducted in South Africa (Monyaluoe et al., 2014) revealed that caregivers expressed positive experiences such as acceptance by living with people with schizophrenia despite their lack of knowledge about the illness.

Lastly, the deinstitutionalisation movement was supported in the US because of the positive effect the new antipsychotic drugs such as haloperidol and chlorpromazine had on patients (Kamal, 2014; Segal & Jacobs, 2013). The drugs reduce the psychotic symptoms and improve the condition of the individuals although the drugs do not cure the illness (Kamal, 2014; Segal & Jacobs, 2013). Turner (2004) attests that the involvement of medication had a significant reduction of mental hospitals and an increase in community-based care facilities.

Deinstitutionalisation happened in the US despite the country having approximately 14.8 million people above the age of 18 years, who are diagnosed with severe mental illnesses (Yohanna, 2013). From this populace, about 2.2 million of the mentioned age group is diagnosed with schizophrenia (Evans, 2009). Additionally, the WHO predicted that the year 2020 will be the greatest burden for mental health (Maiocco et al., 2017). This prediction, including the various reasons provided for deinstitutionalisation in the US and Europe, warrants criticism against the deinstitutionalisation movement for not providing globally inclusive practical solutions such as sufficient mental health workers and community-based care facilities (Lippi, 2016). This could be a possible reason why several countries may have rejected the adoption of the mental health policy as proposed by the WHO. According to Shen and Snowden (2014), from the 193 countries that were studied using the *World Health Atlas* from 1950 to 2011, about 45 countries did not adopt the policy. The assertion is that the 148 countries that adopted the policy were predominantly from the western world (Shen & Snowden, 2014). This amplifies the notion that deinstitutionalisation was not thoroughly thought through and was not inclusive of developing countries.

According to Shen and Snowden (2014), the bone of contention for deinstitutionalisation was to close down psychiatric hospitals. Meaning, gradual reduction of bed capacity for in-patients in psychiatry wards, while simultaneously promoting for community care, which entails integrating psychiatric patients into general hospitals – providing beds for people with mental illnesses in primary health care settings. However, lesser bed availability in psychiatric hospitals did not mean that the demand was lesser for psychiatric services; instead the process rather strategically shifted the responsibility to the family members as caregivers – a role that is naturally embodied in a collective society, and therefore, affects the developing countries more than the developed world (Shen & Snowden, 2014).

In the Asian, Arab and African contexts, the issue of deinstitutionalisation has a significant aftermath. Indonesia, a country with 250 million people, from which 0.17% of the population is diagnosed with schizophrenia, provides bed capacity of 7700 square foot throughout the 48 mental hospitals available in the country (Suryani, 2015). This could imply that the majority of the individuals diagnosed with schizophrenia live with their caregivers at home. Also, schizophrenia is a prevalent mental illness in India. From the one billion population of the country, every third person out of 1000 people in India is diagnosed with schizophrenia, most of them males (Loganathan & Murthy, 2011). According to Daund et al. (2018), the bed capacity increased slightly in mental health institutions across the country over the past 50 years, from 10 000 to 21 000 beds, inferring that there is still a huge disparity between hospital beds and number of patients diagnosed with schizophrenia. Furthermore, the country has limited alternative care systems, which in turn exacerbates the burden experienced by the caregivers who have taken on the care responsibility (Murthy, 2016).

Comparable to India's collective societies, Iranian close-knit family settings that are very interactive and interrelated are also exposed to considerable care burden, in addition to extremely scarce professional support and mental health facilities (Shamsaei et al., 2015).

The African continent has not been spared the impact of deinstitutionalisation. Countries such as Nigeria, Botswana, Zimbabwe, Ghana, Tanzania, South Africa and Namibia, to mention a few, are affected as they too have adopted the mental health policy according to Shen and Snowden (2014). As a result, many countries had to close down or reduce mental health institutions to comply with the mental health policy, a decision that overlooked the implications of reduced beds within this context. Generally, when policies are made initially for certain contexts and passed on to other contexts, economic implications and resource availability for countries adopting policies are rarely considered (Modie-Moroka, 2016). Shen and Snowden (2014) attest to this oversight that had implications for the developing countries, as their evaluation study identified similar findings in the countries they investigated that adopted the mental health policy.

According to Taiwo et al. (2008), a study conducted in Lagos, Nigeria, found that long-staying patients in psychiatry hospitals highlighted the issue of insufficient beds. The study reported that the hospital only had 476 functioning beds. About 10.7% of the beds were occupied by long-stay patients who were predominantly male patients (76%) and by those diagnosed with severe schizophrenia (87.3%) (Taiwo et al., 2008). Most of the patients were either homeless people or individuals whose family members relinquished the responsibility to the institution. As a result, space has become limited for new admissions. New acute cases were treated at the emergency room and were immediately discharged. This meant that patients were sent home without thorough observation for medication response and recovery (Taiwo et al., 2008). These implications are attributed to the current situation of the country. Firstly, because the country’s mental health policy is in a reform process to facilitate deinstitutionalisation, and secondly, because there are not enough community care facilities to absorb the long-stay patients elsewhere (Taiwo et al., 2008).

In South Africa, Trump and Hugo (2006) suggest that, one percent of the population, which is approximately 500 000 people, suffer from schizophrenia as per census estimates. The country has 41 in-patient psychiatric divisions that are integrated into general hospitals with a bed capacity of 2.8 beds for 100 000 people, in addition to the 3.6 bed capacity for 100 000 people in 63 community residential facilities, as well as 23 mental hospitals with 18 beds per 100 000 populations (WHO-AIMS Report on Mental Health System in South Africa, 2007). However, Lippi (2016) argues that the current available resources in terms of community-based care facilities do not meet the demand for people with mental illnesses in the country. Another study conducted in the Kwazulu-Natal (KZN) province not only highlighted that nurses have insufficient training on mental health issues but the hospitals in the area also provided only 25% bed capacity for mental health patients (Sibiya et al., 2019). This places the long-term burden of individuals diagnosed with schizophrenia on family members who are not only uneducated on the subject but are also financially stricken (Lippi, 2016).

To highlight Zimbabwean challenges of deinstitutionalisation, Mlambo et al. (2014) report that the country is continuously faced with incompetently trained mental health professionals and lack of material resources despite their efforts to tackle mental health issues. In hindsight Marimbe-Dube (2013) states that the country decentralised mental health services after the inception of deinstitutionalisation. However, basic resources such as hospital beds for new admissions and a lack of staff persist to be a problem, particularly in rural areas. Marimbe-Dube (2013) further postulated that the country functioned with a meagre staff capacity of 57% at some point, shifting most of the care responsibility of the people with mental illnesses to the family members. Notwithstanding that schizophrenia is the second overriding illness in the country (Mlambo et al., 2014).

From the ensuing literature, Botswana and Ghana seem to be in a better position when it comes to the availability of psychiatric hospitals and bed capacity compared to their African counterparts.

According to Modie-Moroka (2016), Botswana has adopted the deinstitutionalisation policy earlier on compared to most African countries. Hence, they managed to decentralise mental health services, including the building of a new psychiatric hospital (Sbrana) and set up several community health centres throughout the country, while simultaneously integrating psychiatric services in general hospitals and local clinics. In 1990, the country had 308 health posts and 170 clinics throughout the country with psychiatric units attached to almost all of them (Modie-Moroka, 2016). The facilities were managed by trained psychiatric nurses. This achievement remains but a dream for most African countries based on the current statistics.

Despite boasting accessibility to mental health services, Botswana equally reports a high prevalence of schizophrenia. Modie-Moroka (2016) states that 2006 statistics indicated that schizophrenia cases were at 42%; dominant among out-patients of which most of them are males. In retrospect, deinstitutionalisation is criticised for overemphasising the benefits of community-based care without really investing in the after-care of people with mental illnesses post-discharge. The study postulated that psychosocial support and psycho-education of patients and caregivers have been neglected as the mental health treatment is predominantly psychopharmacology focused (Modie-Moroka, 2016). This treatment model seems to have exacerbated the relapse rates at all health facilities, more so, at Sbrana Psychiatric Hospital, because of the high probability risk of medication default which requires readmission among people diagnosed with schizophrenia.

Furthermore, Modie-Moroka (2016) asserts that from the 5073 admissions in 2010 at the Sbrana Psychiatric Hospital, the majority of cases, which constitute 4423 patients, were readmissions, whereas only 650 were new admissions. The readmission inadvertently puts pressure on bed accessibility for patients as only 390 beds (10%) from the 3816 hospital beds available in the country are assigned to psychiatry patients on top of the lack of mental health professionals available in the country (Modie-Moroka, 2016). This picture highlights the flaws within the deinstitutionalisation initiative that strategically places the burden of people with schizophrenia on the ill-informed family members. The group who is predominantly affected by the burden are female caregivers because schizophrenia is more prevalent among males than females (Modie-Moroka, 2016).

Ghana has three psychiatric hospitals namely the Accra Psychiatry Hospital which was built in 1906, followed respectively by Ankaful Psychiatric Hospital in 1965 and Patang in 1975 (Opoku-Boateng et al., 2017). Although the numbers of hospitals are few compared to South Africa and Botswana, the country boasts with a bed capacity of 1450 beds, by far the highest according to the existing African literature for this current study. However, as with most African countries, bed capacity seems to be a challenge for an estimated population of 25 million people. More so, since 32% of the mental health cases treated at these facilities are schizophrenia-related (Opoku-Boateng, et al., 2017).

To further complicate the mental health accessibility in Ghana, it is important to note that all these hospitals are situated in the southern part of the country. This means that mental health services are not inclusive compared to Botswana and South Africa that have decentralised the services to other areas of the countries. The repercussions of the inaccessibility to the mental health services have perhaps seen a majority of the caregiving fall on the shoulders of family members. However, the country is still in pursuit to decentralise its mental health services (Opoku-Boateng, et al., 2017). Interestingly, similar to Botswana, women in Ghana bear the most responsibility in caring for people with schizophrenia.

Namibia, on the other hand, has a much smaller population of 2.5 million people compared to its counterparts; however, it is not immune from the inadequate mental health service challenges. As with most countries, schizophrenia is also rated as one of the common mental illnesses in the country (Dhaka et al., 2017). To substantiate, data disclosed by senior nurses, Nkolonga and Kazarako (personal communication, March 19, 2019) from the Windhoek Mental Health Unit, indicated that between 224 and 337 schizophrenia-related cases were reported on a monthly period, making the illness one of the top three. Furthermore, *News24* (as cited in Dhaka et al., 2017) reported that the country treated 8000 patients with various mental illnesses in 2015. This is despite the country only having 2 psychiatric units in the country with bed capacity of 192 between the two units (Dhaka et al., 2017). Windhoek Central Hospital’s Mental Health Unit respectively has 112 beds. Additionally, the staff at these institutions comprised only 3 psychiatrists, 43 psychiatric nurses, 2 psychologists and 3 social workers (Dhaka et al., 2017).

An article published in *The Namibian* (Kangootui, 2018) disclosed a shortage of psychotropic medication at the Windhoek Central Hospital that left many patients without treatment. This speaks to the disparity gap that exists between resources and the community affected by schizophrenia. One can thus imagine the purported burden experienced by the caregivers, especially, knowing the unpleasant symptoms associated with untreated schizophrenia patients. Namibia's mental health service disparity indicates that the size of a population does not exempt a country from lack of resources or from mental health illnesses such as schizophrenia. Schizophrenia does not discriminate.

The available resources still do not equate the needs of the people with mental illnesses in the country, more so, regarding those diagnosed with schizophrenia, not mentioning the undiagnosed who therefore remain untreated. Hence, sufficient budgeting and all-inclusive affordable medical aid schemes, as well as accessible treatment services are needed to bridge the gap. According to Trump and Hugo (2006), numerous patients who rely on medical aid schemes do not receive adequate treatment because of the restrictions placed on the schemes in terms of the conditions it should treat, the allocation of the medication, as well as therapy consultations. These limitations, subsequently, hinder patients' full recovery process, which inadvertently increase the burden on already overstretched caregivers.

Hence, this present research is significant because the study is positioned against the disparity backdrop in the mental health community. Also, the current study will help gain understanding of first-hand experiences of caregivers and highlight the purported gaps based on the different caregiver needs. Important to note is that the present study fills the gap identified by Kamal's (2014) and Lippi's (2016) studies that shed light on the limited literature on caregivers experiences, as studies were mostly focused on patients' instead of caregivers' experiences thus minimising caregivers' experiences. Similarly, Sibiya et al. (2019) asserts that mental illnesses do not only affect individuals with the illness but also the family members that care for the individuals, as family caregivers play a significant role in the well-being and recovery of those they care for. Furthermore, the current study will advocate for alternative interventions for caregivers to ease access to mental health resources. The hope of the researcher is that this study's outcome may provide a pathway to reduce the burden for caregivers, as well as enhance their quality of lives including those diagnosed with schizophrenia.

2.3 Burden of Schizophrenia

According to Shamsaei et al. (2015) the *World Health Organisation* (WHO) indicated that one out of four families is likely to have a relative with a mental disorder by the year 2020, therefore, the year was predestined as the global mental health epidemic year. In addition, Cabral et al. (2016) postulated that schizophrenia specifically is associated with long term social burden and has a high prevalence rate worldwide. The illness is considered to be among the top ten most debilitating illnesses as the individuals diagnosed with schizophrenia are prone to be disorganized and dependent on others, and would therefore need the intervention of family support. The caregivers' burden is further maintained by the deinstitutionalisation process that has seen many family members assuming the caregiver role globally (Kamal, 2014). In concurrence, De Sousa et al. (2012) suggest that 30-85% of adults with schizophrenia are cared for by family members, and that those living at home with chronic schizophrenia vary between 50-90% (Riley- McHugh, et al., 2016).

Considering that family members are the primary caregivers in most cases, it only makes sense to view the burden from a family perspective. According to Platt (as cited in Lowyck et al., 2004, p. 383), a burden within a family context, is explained as “the presence of problems, difficulties or adverse events which affect the lives of the psychiatric patients' significant others, for example, the members of the household and/or family". On the other hand, Heru (2000), Lippi (2016) and Oshodi et al. (2012) view burden from an objective and subjective lens. These scholars posit that objective burden is concerned with the physical (tangible) challenges caregivers may experience in caring for relatives with schizophrenia, such as financial expenses and/or changes in everyday life program of the family, for instance absenteeism from work, attending medical appointments, or even neglect of self (Sibiya et al., 2019). Whereas subjective burden is described as the view of the self (caregivers) and how they perceive their lives in caring for their relatives with schizophrenia and the degree to which they are affected (Heru, 2000; Lippi 2016; Oshodi et al., 2012), subjective burden involves the physical and psychological health of the caregivers as it often presents itself through anxiety, depression, guilt or worry (Cabral et al., 2016; Evans, 2009; Kamal, 2014; Lowyck et al., 2004; O’Brien, 2005).

2.3.1 Psychological Burden and Physiological Health of Caregivers of Schizophrenia Patients’

According to Riley-Mchugh et al. (2016), caregivers, as high as 90%, experience a moderate to severe burden, with those caring for individuals diagnosed with schizophrenia specifically at higher risk of developing mental disorders, such as depression and anxiety compared to those caring for dementia patients. In support of the burden experienced by caregivers, a study conducted in Portugal asserts that 63.5% of the female caregivers exhibited signs of moderate depression while affected male caregivers were 37.5% (Cabral et al., 2016).

Another study by Caqueo-Urízar et al. (2017) proposes that schizophrenia caregivers' mental and physical health is gravely compromised compared to non-caregivers or those caring for people with Alzheimer's disease or epilepsy. A Canadian study that focused on mothers' experiences viewed schizophrenia through a family perspective and suggest that the illness is indeed a family illness as it affects everyone (Milliken, 2001). Caregivers in this study were predisposed to sleep-related disorders and physiological illness such as hypertension, heart attacks, and sporadic chest constrictions on top of the psychiatric illnesses.

Furthermore, Riley-Mchugh et al. (2016) postulated that the diagnosis stage was more emotionally provoking as caregivers expressed various unpleasant emotions immediately after learning about the diagnosis of their relative. On the contrary, Caqueo-Urízar et al. (2017) implicated the progression of the illness as one of the greatest phases that have psychosocial affliction on the caregivers. To support caregivers' psychological distress, Heru (2000, p. 96) posits that caregivers expressed a sense of hopelessness, feelings of loss and grief as well as inadequacy; inability for not doing enough for the ill relatives and guilt over the spread of the illness.

Additionally, age of onset and the help-seeking experiences of caregivers were also implicated in the heightened distress (Riley-Mchugh et al., 2016). Caregivers in this study voiced conflicting feelings such as fear, guilt and relief in their encounter with the service providers. According to Veltman et al. (2002, p. 110), all caregivers in their study at some juncture experienced both pleasant and unpleasant feelings, such as confusion, fear, love, sympathy, sadness, resentment and compassion in their caregiving. Heru (2000) suggests that subjective affliction is more distressful for caregivers than material responsibility or symptomology.

However, Kamal (2014) states that symptomology has dire emotional triggers for caregivers. The disturbing behaviour displayed by people with mental illnesses can elicit mental and psychological suffering for caregivers. To agree with the implications caused by behavioural problems in schizophrenia patients, Ferriter and Huband (2003) confirmed that verbal aggression and violence were frequently described as causing shame, distress, as well as instilling fear in caregivers. For example, a family member in the study said the following on aggressive behaviour displayed by a relative with schizophrenia "*a terrifying experience . . . the energy that's there and it's malevolent but like, if you keep still, nothing is going to happen – you just got to keep it calm . . . the more you said . . . the more aggressive he became"* (Ferriter & Huband, 2003). Additional behavioural problems that contributed to significant burden among caregivers were the unusual sleeping patterns of the patients that involved day time sleeping and being awake at night, and destroying of furniture, engaging in monologues, and non-stop talking (Kamal, 2014).

In line with their counterparts, Arab, Asia and Africa are not exempted from the psychological and physiological stressors that result from caring for people with schizophrenia. Numerous studies conducted within these contexts postulate that developing countries and collective societies are predisposed to substantial burden because of their economic and societal structures (Ae-Ngibise et al., 2015; Lippi, 2016; Shamsaei et al., 2015; Suryani 2015). The subjective and objective burden seems more rampant among caregivers of schizophrenia as opposed to those caring for people with depressive disorders, bipolar disorder and obsessive-compulsive disorder or other long-lasting physical ailments (Lippi, 2016). In agreement, Stanley et al. (2017) Indian study state that schizophrenia diagnosis is correlated with substantial suffering for family members.

According to Shamsaei et al. (2015), Iranian caregivers found taking care of physically disabled people more favourable than those with chronic mental illnesses. The majority of the caregivers experienced stress in their role as carers; however, the most susceptible ones were the carers whose mental health was compromised due to the caregiving. The caregivers in this study expressed feeling enormous stress and sadness because of the uncertainty associated with the prognosis as well as the future coping abilities of the ill relatives in the absence of the carers (Shamsaei et al., 2015). Additionally, caregivers attributed their physical conditions such as migraine, gastritis, chest pain and high blood pressure to the stress associated with caregiving.

An Indonesia study revealed that caregivers reported feelings of hopelessness and frustration when there was no emotional or financial support (Suryani, 2015). Also, caregivers feared for their safety and that of other family members especially, when there was a history of destructive or violent behaviour displayed by the relatives with schizophrenia. A caregiver narrated "*I was being almost killed by my son who was wielding a knife*" (Suryani, 2015, p. 5). A study conducted in India with spouses diagnosed with schizophrenia indicated that the stress experienced by family members was more intense when the ill relatives were males (Kumar & Mohanty, 2007). The feelings expressed by female caregivers were exhaustion, frustration, isolation anxiety and hefty workload, besides the financial strain and domestic responsibilities. .

A Nigerian study found that nearly half of the caregivers experienced emotional distress with extra burden felt in most caregivers in their role as carers (Oshodi et al., 2012). Although the majority of the caregivers felt supported by the health professionals, those that felt inadequately supported suffered the most psychological distress. Perhaps, as a result, numerous caregivers wished that the ill relatives were never born and/or that they were better off dead (Oshodi et al., 2012). Likewise, caregivers in Ghana, who were mostly carers of schizophrenia relatives, reported that their emotional triggers were linked to the behaviour of their relatives (Ae-Ngibise et al., 2015). Some caregivers expressed that they endured sleepless nights because of the symptomology of the ill relatives, such as crying and/or talking throughout the night, while others highlighted abusive and violent behaviour as reasons for emotional distress. Similarly, Tanzanian caregivers correlated the anxiety they felt with the violent behaviours shown by ill relatives, as well as the disappearance from homes that lasts for many weeks, which further fuelled the anxiety experienced by caregivers (Iseselo et al., 2016). This meant that caregivers generally spend significant time and effort in search of their relatives.

According to Lippi (2016), psychological burden experienced by caregivers in South Africa have been connected with insufficient resources such as community services. However, Monyaluoe et al. (2014) assert that aggressive and violent conduct of ill relatives experienced by Indonesian caregivers was identified as causality for emotional turmoil among South African caregivers. Caregivers in the latter context felt vulnerable as they feared for their lives. They were concerned with either being injured or killed by their relatives (Monyaluoe et al., 2014). Additionally, the caregivers found ill relatives' unusual behaviours such as undressing in the public difficult and embarrassing to watch. Similar to Iranian and Canadian caregivers' experiences, South African caregivers narrated that living together with their relatives with schizophrenia affected their mental and physical health severely. Hence, some caregivers in this study were on depression, stress and high blood pressure treatment (Monyaluoe et al., 2014).

Despite the limited literature available on mental health in Namibia, a recent study conducted on both the families' and patients' experiences on mental health, revealed that caregiving is an emotionally daunting task for family members because of the patience and tolerance it requires (Shifiona et al., 2019). As with caregivers in South Africa, some family members lived in constant fear of their lives even when relatives with mental illnesses were manageable, because of the unpredictable relapse episodes that could cause tremendous harm to the caregivers and patients. Also, parents of individuals diagnosed with mental illnesses experienced self-blame and guilt as they felt responsible for the genetic passing on of the illness to their children (Shifiona et al., 2019). To this, Dhaka et al. (2017) proposed that psycho-education and service accessibility need to be strengthened in sub-Sahara Africa in order to equip general public.

2.3.2 Everyday Life Challenges of Caring for People with Schizophrenia

Apart from the emotional distress, family caregivers' overall well-being and quality of life is compromised because of the daily tasks involved in caregiving (Caqueo-Urízar et al., 2017; Kamal, 2014; Milliken, 2001). According to Van Rensburg (2013, p. 7) well-being is explained as personal levels of poverty, life quality and material needs, whereas quality of life is understood as a measurement of the caregivers' well-being and health in different aspects of their lives Caqueo-Urízar et al. (2017, p. 3). These aspects involve emotional reactions to life occurrences, disposition, sense of life fulfilment, satisfaction with work and personal relationships of individuals with others (Theofilou, 2013, p. 151). Therefore, in as much as quality of life may have a subjective component, the objective influences, such as unemployment or homelessness, cannot be negated because they contribute to the poor quality of life for the carers, which in turn affect the caregiving process.

Pejlert (2001) stressed that although caregiving may have positive aspects, the negative effects are that caregivers who are committed and active in their roles often forfeit their personnel needs in exchange for pursuit of a loving relationship with their ill relatives. A Canadian study that investigated the experiences of parental carers found that parents that were completely immersed in the caregiving role offered unlimited practical, monetary and social support because of the dedication to their children (Milliken, 2001). As a result, many caregivers' experiences were more unpleasant as opposed to pleasant in this study. Additionally, most caregivers invest a huge amount of time by being watchdogs in an attempt to protect their loved ones and in seeking help for them (Pejlert, 2001).

Similar to the western context, the African carers' quality of life is also affected because of the economic burden and lack of social support caregivers experience in usually collective societies because of the stigma attached to schizophrenia in (Opuko-Boateng et al., 2017). The only group of people, who seemingly appear to have an increased quality of life compared to their counterparts, are the married people and those educated in the subject matter of schizophrenia (Opuko-Boateng et al., 2017). Within the Namibian context, lack of resources is implicated in the caregiving burden particularly in the day-to-day life of the caregivers (Shifiona et al., 2019). This finding resonates with numerous studies on the continent.

2.3.2.1 *Financial Burden Associated with Caring for People with Schizophrenia*

Of the many objective burdens experienced by caregivers, the financial burden seems predominant among most carers of people with schizophrenia. Maiocco et al. (2017) assert that schizophrenia is known worldwide for bearing hefty economic impact on the governments and broader societies. The financial cost including treatment and other expenses varies from between $32 and $65 billion yearly globally (Maiocco et al., 2017).

Kamal's (2014) study states that the financial burden causes significant distress for family caregivers in the United States. The fiscal burden was attributed predominantly to the symptomology of schizophrenia such as lack of social and life skills that disables the ill individuals from taking up employment or remain employed. In agreement with the expenses associated with schizophrenia, Milliken (2001) voiced that schizophrenia is a costly illness in Canada as parents of children with schizophrenia incur the biggest financial loss because of the additional psychotherapy and medical cost they have to pay since the Canadian medical insurance only covers for the basic expenses. Some parents suffer further costs when their children disappear from homes as they have to pay for flights, distance calls in an attempt to locate their children, and sometimes spend money to bail out the children when they find themselves in trouble with the authorities. Compared to the $89 mentally ill grant offered by the Canadian state, parents spend more money in caring for their children with schizophrenia (Milliken, 2001).

To concur with the financial expenditure involved, a Belgium study that comprised of 150 participants disclosed that caregivers' greatest burden was the financial cost (Lowyck et al., 2004). The study suggests that the situation was dire as some parents of children with schizophrenia had to avoid calculating the cost because of the fear of being perceived as upset for spending the money on their children. According to Lowyck et al. (2004), caregivers' monthly earnings vary between 496 and more than 2479 euros. However, the annual caregiving cost for the previous year was calculated at 2623 euros, which indicates that schizophrenia related expenses are beyond the caregivers' earnings. Hence, many parents have prompted the mental health fraternity and the government to be conscious of the cost involved in caring for people with schizophrenia (Lowyck et al., 2004).

Likewise, an Iranian study identified financial strain as the ultimate burden among the majority of the caregivers (Shamsaei et al., 2015). Shamsaei et al. (2015) posit that most caregivers are unemployed or have abandoned their jobs due to caregiving responsibilities; as a result they do not have a stable income. Caregivers live off loans and hand-outs (Shamsaei et al., 2015). Therefore, caregivers are puzzled by the spending habits of their relatives with schizophrenia who spend already scarce financial resources on excessive smoking, while basics such as food and clothing still need to be covered.

In the African context, Ghana treats about 32% schizophrenia cases (Opuko-Boateng et al., 2017). The monthly expenses estimated in caring for people with schizophrenia are US$273.28, of which the medical cost amounts to US$30.36. The majority of the money, which is US$242.95, is for non-medical costs and covers expenses such as transport, food and other unforeseen household activities relating to caring (Opuko-Boateng et al., 2017). As a result, substantial financial and social burden is carried by caregivers caring for their relatives with schizophrenia, despite them losing out on job opportunities because of the care role, which in turn, affects their economic standing (Opuko-Boateng et al., 2017). In agreement, Ae-Ngibise et al. (2015) argues that most caregivers are jobless or are either peasant farmers who often sell off their personal belongings such as clothing items to remedy the financial hardship. Alternatively, distant family members offer help but this is also minimal.

Similarly, Tanzanian caregivers are not immune to the psychosocial burden associated with caring for people with mental illnesses although the country does not have evidence-based data available on people with mental illnesses yet (Iseselo et al., 2016). Family members embodying the caregiving role experience various challenges of which the financial cost is one of them. Caregivers spend a lot of money on transport costs to and from the health facilities and medication because of the lack of resources available at the state health facilities (Iseselo et al., 2016), This means that caregivers have to buy medication from private entities such as pharmacies, incurring additional expenses (Iseselo et al., 2016). Perhaps it is safe to allude that the medical cost concerns experienced by caregivers in this context is comparable to that of many caregivers' experiences in Ghana and Belgium.

Although Namibia has no empirical evidence on the financial cost of schizophrenia, inferences can be made from other African countries. Namibia and Tanzania specifically, share literature that speaks to the shortage of anti-psychotic medications at state facilities. Therefore, it would make sense to assume that perhaps caregivers of relatives of schizophrenia also incur financial costs in their role as carers.

2.3.2.2 *Loss of Time*

The time invested in caregiving has been identified as a challenge for the caregivers (Caqueo-Urízar et al., 2017). Because of the demanding tasks of caregiving, many caregivers are deprived from engaging in social and relaxing activities (Kamal, 2014). Additionally, some caregivers had to adjust their work schedule and take on part-time employment or completely abandon their paying work in order to care for their relatives with schizophrenia. Caregivers' time is mostly spent on accompanying their loved ones to doctor's appointments, cooking meals for them and ensuring that relatives take their medication as prescribed (Milliken, 2001).

In the Asian context, Stanley et al. (2017) mentioned that 70% of the people diagnosed with schizophrenia live with their family caregivers as it is a natural process for family members to care for their ill relatives. As a result, caregivers in India are highly likely to carry the burden associated with caregiving. From the various burdens experienced by caregivers, disturbances in caregivers' daily schedule, such as going to work and/or spending time with other family members, have been correlated with severe burden because caregivers spend a great amount of their time looking after their ill relatives, leaving them with limited time for themselves (Stanley et al., 2017).

Within the African context, a study conducted in Nigeria by Oshodi et al. (2012) that predominantly consisted of schizophrenia carers, show that physical burden is most prominent among the caregivers. Caregivers dedicate substantial time towards their relatives with schizophrenia by carrying out everyday tasks such as preparing food and cleaning, as well as assisting in the medication administering process. These duties often take a toll on family caregivers because of the high dependency of some ill relatives on the carers. Parents, in particular, are mostly affected because they spend about 11 hours a day on caring duties, approximately 39 hours a week (Oshodi et al., 2012).

Similarly, Ghanaian caregivers expressed frustration as they felt mostly affected by the illness because of the time consuming care activities that involve bathing, feeding and nature call assistance of the ill relatives (Ae-Ngibise et al., 2015). Caregivers in the study felt that caregiving duties take up most of their time. Also, caregivers implied that the responsibility associated with caregiving will continue unless a cure is found for schizophrenia. The literature provided in this present study indicates that schizophrenia has no cure, therefore, the majority of caregivers are likely to occupy the caregiving role longer than anticipated, and for some carers the role may be lifelong task.

Parents in a Tanzanian study concur to having limited time for other family members' needs, despite having multiple roles as parents (Iseselo et al., 2016). This can be ascribed to disruptions in the household that come about as a result of the caregiving for relatives with schizophrenia. A caregiver in the study expressed that the bulk of their time is spent on care related duties because their relative with schizophrenia completely relies on them for every day functioning.

According to Leech and Dolamo (2016), South African caregivers are often deprived from attending social events because of the time taxing responsibilities attached to the caring of people with schizophrenia. Namibian caregivers, on the other hand, stated that they often had to take turns in caring for their ill relatives because of the pressure affiliated to the role, which sometimes lead to absenteeism from work as they have to accompany their ill relatives to doctors' appointments (Shifiona et al., 2019). The absenteeism from work, in turn, not only compromises the productivity of the caregivers but also bears consequences for the rest of the family members who are depending on the caregivers' income.

2.3.2.3 *Social Isolation*

Furthermore, caregivers were burdened with social isolation in their role as carers. Social isolation is defined as a psychological or physical withdrawal of individuals from larger societies or systems, which they need support from (Biordi & Nicholson, 2008), which can inadvertently elicit social pain for such individuals (Cacioppo et al., 2011).

Caqueo-Urízar et al. (2017) and Kamal (2014) postulate that caregivers experience social isolation because of the stigma attached to the mental illness and the presence of the illness in their family. More than one-third of schizophrenia caregivers noted that there is a detachment between them and other family members because of the presence of schizophrenia (Caqueo-Urízar et al., 2017). Ultimately, the detachment creates lack of social support for the caregivers that could make the caregiving experience difficult for the caregivers. Kamal (2014) suggests that caregivers either exclude themselves from attending community events or are excluded from social events by community members because of the strange behaviours associated with the illness that is exhibited by the ill relatives at social gatherings, which is found to be embarrassing by others.

In agreement, Iranian caregivers mentioned that they often felt unsupported and misunderstood by family members and neighbours in their role as carers of schizophrenia relatives because of the stigma attached to the illness (Shamsaei et al., 2015), which resulted in isolation.

Likewise, caregivers in Indonesia communicated experiencing difficulties in forming social relationships because of the demanding task of caregiving that requires time from them (Suryani, 2015). Additionally, the unpredictable inappropriate behaviour of the persons with schizophrenia, such as fighting and screaming in public were seen as deterrents for the carers from engaging in social activities. The exclusion from social activities reduces caregivers' chances of building potential interpersonal relationships with others and subjects them to the stigma attached to the behaviour of the ill relatives (Suryani, 2015).

Corresponding with the sentiments shared, Tanzania caregivers also expressed a lack of social support from extended family members and wider communities, especially, with the presence of mentally ill relatives in families (Iseselo et al., 2016). Iseselo et al. (2016) posits that the usually collective family units become smaller and more nuclear when mental illness is involved and that the burden is felt significantly by smaller nuclear families compared to when the burden was shared. Furthermore, the responsibility associated with caregiving deprives parents/caregivers from forming friendships as they are often shamed, blamed and socially rejected because of the mental illnesses (Iseselo et al., 2016). This, inadvertently, affects their social lives as many family members live in isolation and do not have sufficient psychosocial support which could serve as an enhancer for a better quality of life but also help them in coping with schizophrenia. These factors contribute to hopelessness and withdrawal that affect the caregiving process and further perpetuate the burden of emotional and financial cost (Iseselo at al., 2016).

In South Africa, the stigma associated with mental illnesses has dire repercussions for caregivers. Caregivers are purposely excluded from the communities because of their association with people suffering from mental illnesses (Sibiya et al., 2019; Nxumalo & Chunu 2017). Community members are fearful that the unpredictable behaviour of individuals diagnosed with schizophrenia may cause either damage to their personal properties or disrupt social events that caregivers are invited to if the ill relatives accompany their caregivers to these events (Sibiya et al., 2019). The volatile behaviour of people with mental illnesses has also been identified as a reason for stigma and social exclusion from community members towards caregivers in Namibia (Shifiona et al., 2019). Family members in this study said that they felt socially disconnected and are even stigmatised by community members who know about their ill relatives' condition.

2.3.3 Coping and Support

According to Rafiyah et al. (2011), the most significant caregivers for people diagnosed with schizophrenia are family caregivers. The study postulated that a populace of schizophrenia between 60% and 85% are cared for by family caregivers and that coping techniques are integral in the maintenance of the caregivers' well-being (Rafiyah et al., 2011). Caregivers' stress levels will determine the type of care received by the ill relatives, whether it will be good or poor. Hence, Pejlert (2001) positions caregiving as a reciprocal relationship. The scholar posits that the familial relationships were previously blamed for causing and exacerbating schizophrenia among the ill relatives. However, newer studies indicate that there is a paradigm shift in the way caregivers are perceived in their role as carers, in relation to the prognosis of schizophrenia. Trivedi (2002) asserts that relapse rates have dropped enormously among people with schizophrenia because of the involvement of family members in the care and support of the ill individuals.

In order to better care for their relatives with schizophrenia, caregivers engage in various activities in their caregiving role to cope with ill relatives and their illness (Kamal, 2014). Caregivers' coping activities include travelling regularly on holidays, spending their time with friends, attending concerts and engaging in hobbies. For some caregivers simple tactics such as adjusting the manner in which they communicate to their loved ones, such as careful selection of words, help in keeping the peace as well as prayer and humour. A study conducted on the benefits associated to caregiving of people with mental illnesses suggest that 70% of caregivers have become more empathetic towards people with disabilities, while 50% of caregivers were able to prioritise time to important matters in life such as family (Chen & Greenberg, 2004). Additionally, caregivers reported on gaining increased patience, understanding, fulfilment and building resilience in their caregiving role

A Swedish study that focused on parents with children with schizophrenia, found that accepting the illness, and being hopeful for better prognoses for their children, as well as concentrating on what was going well in their lives helped these parents to cope better with their situation (Pejlert, 2001). Other coping methods identified in this study were having communicative relationships with staff members, being knowledgeable in the treatment plan of their children and engaging in regular conversations with other parents in similar situations. These coping methods were considered immeasurably helpful for parents. In addition, attending church and having family support were considered to be comforting (Pejlert, 2001).

On the contrary, an Iranian cross-sectional study showed that 54% of schizophrenia caregivers use maladaptive coping strategies (Rahmani et al., 2019). According to the study, younger people with lower education and poor socioeconomic backgrounds used emotionally focused coping strategies. For example, caregivers used avoidance to cope with the situation. Avoidance is generally applied when caregivers want to escape the stress affiliated with caregiving tasks, however, in retrospect, this style may elicit depression among caregivers if the avoidance continues longer because then coping becomes ineffective (Rahmani et al., 2019). The emotional coping strategies were found to be predominant among women compared to men, who relied on problem-solving techniques. Furthermore, the study asserts that caregivers were reluctant to seek information on schizophrenia and treatment of it (Rahmani et al., 2019).

In the Asian context, a Taiwanese study disclosed that caregivers engaged in various coping mechanisms, and that the common coping styles for caregivers for people with schizophrenia were psychological, social and physical (Huang et al., 2008). These scholars posit that caregivers applied coping methods based on their social status and that the majority of caregivers came from low social status, economically and educationally. According to Huang et al. (2008), the latter group of people were likely to engage in emotion-focused coping, such as crying as they saw their situation fatalistic with no hope for solutions. In contrast, people with higher social status applied a more problem-focused approach, which was predominantly cognitive and involved positive thinking and psycho-education. Problem-focused approaches helped caregivers to accept schizophrenia as the diagnosis for their ill relatives, and made the coping outcome better for the caregivers (Huang et al., 2008).

Furthermore, people with minimal social support from friends, family and neighbours were likely to depend on religion as a coping method. However, Indonesian caregivers who received more social support fared better psychologically and physically because people around them enabled them to share their problems and they received guidance on how to solve problems relating to their situation (Rafiyah et al., 2011). Also, believing in God played a significant role among caregivers in Indonesia as faith helped them to conceptualise the problem from God’s perspective, which made the coping experience easier because they found meaning and purpose in their relationship with God. In comparison to Taiwanese caregivers that used the problem-solving coping technique, Indian caregivers of whom the majority were spouses of people with schizophrenia, used emotional coping as a pathway to accept the illness (Parasar et al., 2015). Akin to Iranian caregivers, the emotional coping was highly correlated with women compared to male caregivers in the Indian context (Parasar et al., 2015).

The coping mechanisms of caregivers in Africa are not that different from those in the West and Asian contexts. Caregivers in Ghana depend on prayers from pastors and divine healers as coping strategies (Ae-Ngibise et al., 2015). Additionally, caregivers draw their strength from being optimistic about miracles and having the expectation that new treatment methods will be released to curb the stress associated with caregiving. In Tanzania, caregivers also ascribed to prayer as a support of hope and encouragement but have also learned to accept schizophrenia as with Taiwanese and Indian caregivers, in order to not build resentment or be disappointed in the behaviour of the ill relatives (Iseselo et al., 2016). As an alternative coping mechanism, some caregivers sought comfort in traditional healers, which was not successful but has instead directed them to seek professional help that produced some satisfactory results for some caregivers. However, coping in general has not been easy for other caregivers as there was a sense of destitute and helplessness primarily due to financial restraints, but also because of the on-going problematic behaviour of the ill relatives, which demotivated caregivers to invest in the caregiving process (Iseselo et al., 2016).

Similar to many caregivers in other contexts, believing in the power of prayers as a strengthening tool is also common among South African caregivers (Sibiya et al., 2019). And as with most African traditions, some caregivers have sought help from traditional healers to cope with the schizophrenia, while others relied on professional help (Monyaloue et al., 2014). In the same manner, Namibian caregivers also employed the help of traditional healers out of desperation for their ill relatives to be healed (Shifiona et al., 2019). Caregivers felt unsupported in their local communities but also experienced inadequate help from professional health workers, and instead viewed the psychiatry ward as a trigger ground that exacerbated the illnesses of their loved ones.

2.3.4 Caregivers' Needs and Interventions

According to Huang et al. (2008), to assure successful support for family caregivers and their ill relatives, understanding the caregiving dynamics is imperative; otherwise service providers and the state may unintentionally increase the caregiver's burden. Caring for people with schizophrenia brings severe stress for caregivers to the extent that stress associated with caregiving is used as a human model measurement for on-going stress in the stress literature (Shamsaei et al., 2015). In an attempt to decrease the burden associated with caregiving, psycho-education and community care programs have been considered as being beneficial in the coping outcome of the caregivers (De Sousa et al., 2012). To corroborate on the benefits of psycho-education, Suryani (2015), states that family-focused psycho-education has enabled family caregivers in becoming more helpful in enhancing the ill individuals' capabilities, but also accepting their behaviour. Additionally, outpatient caregivers' support groups have been found to create a sense of oneness as well as instilled hope among caregivers because of the shared experiences at outpatient facilities during the meetings (Purba, 2017). The study also identified improved social skills among patients with schizophrenia who received rehabilitative intercessions compared to those who did not receive intercessions. The social skills enhancement programs included aspects such as career training and occupational psychotherapy (Purba, 2017).

Nevertheless, the above improvements do not overwrite the existing great need for interventions that could curb the burden experienced by caregivers (Caqueo-Urízar et al., 2017; Chen & Greenberg, 2004; Milliken, 2001; Pejlert, 2001). These scholars concluded that the majority of family caregivers are still uneducated and lack sufficient training on the management of people with schizophrenia. Further on the study highlighted the incompetence of the mental health professionals in how they disseminate information and interact with caregivers (Milliken, 2001; Pejlert, 2001). Although, some caregivers shared positive experiences such as receiving compassion from health workers, other caregivers reported feeling ignored and neglected by health professionals (Riley-Mchugh et al., 2016).

A study conducted in the United Kingdom with parents of children with schizophrenia, also revealed receiving negative treatment from the health professionals, more so, from those trained in the mental health field (Ferriter & Huband 2003). These caregivers narrated that they received better help from other service providers like the police or self-help groups as opposed to mental health workers. The insufficient help rendered by health workers continued to subject many caregivers to substantial burden, which inadvertently affected their overall health. To remedy the poor service experienced by caregivers from service providers in Belgium, Lowyck et al. (2004) proposed that the entire family units of relatives with schizophrenia be included in the psycho-education sessions. The all-inclusive education was purported to provide t accurate information on the different aspects of schizophrenia for all family caregivers but also to ensure that transparency existed between the caregivers, the ill relatives and the service providers.

Similarly, Iranian scholars pointed out that health professionals disregard the family members' role in the caregiving of schizophrenia relatives hence caregivers have limited information about the illness; prompting that consideration be given to caregivers' needs and problems (Rahmani et al., 2019; Shamsaei et al., 2015). This study posits that health professionals should provide adequate training to caregivers on how to care for people with schizophrenia and provide detailed psycho-education about the symptoms; cause, prognosis and medication including the side effects of medication. Also, caregivers should be involved in the treatment plan of the ill relatives, be able to access health resources at hospitals and societal level and that health professionals need to be reachable to answer questions caregivers may have on schizophrenia (Rahmani et al., 2019). Furthermore, caregivers expressed a need for informal and formal social support from families and friends, as well as from health workers, and financial support from the government as many caregivers are unable to cater for their loved ones because of financial hardships (Shamsaei et al., 2015).

The exclusion from psycho-education and family-inclusive treatment of relatives with schizophrenia is also felt among Asian caregivers in India and Indonesia as with other contexts (Parasar et al., 2015; Suryani, 2015). Correspondingly, caregivers from Taiwan mentioned the lack of communication that exists between them and the health workers and that they feel unsupported professionally compared to the assistance they get from friends and family (Huang et al., 2008). Therefore, the need to understand caregivers' experiences and to provide them with psycho-education, family therapy and family support groups have been emphasised to health workers, not excluding the cultural and religious elements, as these are important components for caregivers in these contexts (Paraser et al., 2015; Suryani, 2015). The government was also encouraged to implement supportive mental health programs by training mental health professionals to meet the needs of the caregivers, and to adhere to the WHO mental health budget allocation as suggested. According to Suryani (2015), each country is supposed to allocate three percentile of their health budget to mental health services; however, India is currently only allocating nine billion rupiahs from its health budget of 21 trillion rupiahs. This indicates the lack of emphasis placed on the significance of mental health and issues surrounding it.

Suryani (2015) postulated that caregivers be provided with paid respite care; to release them occasionally from caregiving responsibilities as these duties can be exhausting, which bears potential health implications for this populace. To highlight the health related risk of schizophrenia caregivers, Shamsaei et al. (2015) assert that caregivers of people with chronic mental illnesses experience a one-third spike in undesirable health signs after taking on caregiving roles. This causes many caregivers to rely on prescription drugs compared to those who are not caregivers. In an attempt to ameliorate caregivers' burden, a Family Intervention Program that encompasses problem-solving skills, constructive coping mechanisms and enhanced interaction skills training, as well as family therapy and environment control is suggested (Parasar et al., 2015). Also, introduction of telephonic interventions for schizophrenia caregivers was proposed because of its effectiveness among caregivers of dementia relatives, in conjunction with short follow-up consultations (Amaresha et al., 2015). These scholars assert that telephonic consultations will particularly be helpful when caregivers experience emergencies with their ill relatives, such as psychotic episodes or drug interactions.

Contrary to the negative interactions experienced by most caregivers with health workers in different contexts, Nigerian caregivers seem to have positive experiences with health workers. According to Oshodi et al. (2012), the majority of the participants in their study felt sufficiently supported by professionals and expressed that support was broad in terms of family members, state entities and employers. However, despite, the positive experiences reported, a need for local family support organisations was identified as a coping mechanism for caregivers (Oshodi et al., 2012). Furthermore, Taiwo et al. (2008) proposed person-centred centres or less restrictive mental institutions like "rehabilitation villages" to absorb the mentally challenged individuals, who the majority are schizophrenia patients dumped by their caregivers at the long-stay hospital.

In an opposing view to Nigerian caregivers, Ghanaian caregivers mentioned experiencing no support except for the limited support they receive from informal sources (Ae-Ngibise et al., 2015). Hence, caregivers in this context placed a demand on the local government and respective stakeholders to provide a broad social support system for affected caregivers in the form of counselling, and public awareness about mental illnesses as the psychiatry services in Ghana are almost dormant (Ae-Ngibise et al., 2015). This is despite the country having three psychiatric hospitals with the most bed capacity in Africa, according to this literature. A reminder that having resources do not equate accessibility and adequate provision of services for people with mental illnesses and their caregivers. Additionally, caregivers task the government to reduce the financial hardship experienced by caregivers by either providing a living allowance or setting up alternative funding for caregivers in a form of loans to enable them to participate in entrepreneurship initiatives to sustain themselves (Ae-Ngibise et al., 2015).

Tanzanian caregivers seem to share conflicting experiences from health professionals. Although there is a strong sense of feeling unsupported both in the informal and formal setting, most of the caregivers stated that they experienced positive interactions with health workers whenever they access the mental health services (Iseselo et al., 2016). Additionally, these scholars suggested that integration of mental health services into the mainstream hospitals is necessary and should be similar to what has been done in Botswana and South Africa, in order to make services accessible and affordable for the caregivers of people with schizophrenia. The study proposed that the government supply free medication and treatment as stipulated in the National Mental Health Policy because caregivers cannot afford to spend additional money on medication for their relatives with mental illnesses (Iseselo et al., 2016). In addition, the government was tasked to provide staff training in the mental health sector to alleviate the existing gap of inadequate services affecting the caregivers and their ill relatives, as well as to provide broad psycho-education on mental illnesses in general, including symptoms, etiology and treatment to curb the stigma surrounding mental illnesses.

Within the South African context, although, insufficient resources such as community mental health services have been correlated with the burden experienced by caregivers; the reluctance among caregivers to share the challenges they experience in their caregiving roles with mental health professionals, may exacerbate the burden experienced by caregivers (Lippi, 2016). In opposition of this notion, a Free State Province study that consisted of 14 participants revealed that participants yearned for a pro-active approach from health workers and to be included in the psycho-education, particularly on the issues of relapse management, non-adherence to medication and aggressive behaviour displayed by their relatives with schizophrenia (Monyaloue et al., 2014). To concur with the caregivers' challenges with health workers, Sibiya et al. (2019) asserts that health professionals' abrupt attitude towards people with mental illnesses serves as a blockage for help-seeking behaviour among this populace, In addition, limited health workers and health programmes are barriers to the well-being of people with schizophrenia and inadvertently their caregivers. Nurses in particular, were identified incompetent because of their lack of training in mental health issues as they can rarely inform or train caregivers on the subject of schizophrenia; not to mention manage or treat schizophrenia.

Hence, Lippi (2016) proposed that individual interventions be done with patients and caregivers but also collectively as a family unit to intersect the nuances of different needs caregivers and ill relatives may have. Interventions such as behavioural family therapy that focus on stress management and goal achievement; multiple family group therapy that taps into problem-solving skills; as well as peer-led family support and a 12-week psycho-educative programmes that include mentoring, coaching and guidance, were suggested. To support the strengthening of caregivers, Monyaloue et al. (2014) proposed that mental health workers promote rehabilitation programmes and conduct home visits that will provide them with insight on family dynamics as it occurs in peoples' homes but also, to apply a multidisciplinary approach in understanding and treating mental health issues. Cultural and spiritual support, including, traditional healing were encouraged as part of a holistic approach to be married with the existing treatment model (Sibiya et al., 2019). However, this integration is to be aligned with the Mental Health Care Act 17 of 2002, as stipulated in the mandate (Sibiya et al., 2019). Additionally, the scholars posit that caregivers could benefit from an increased social grant fare and emotional support.

From the above literature, it can be deduced that the needs and interventions for Namibian caregivers may be similar. According to Shifiona et al. (2019), Namibia has very few mental health resources such as health workers. This does little to ease the burden experienced by caregivers and rather exacerbates the burden for caregivers because people with mental illnesses are kept in isolation rooms when they are institutionalised; meaning they do not receive adequate care from health professionals. As a result, the ill persons' condition worsens upon discharge, positioning psychiatry wards as breeding grounds for psychotic episodes that pose as a threat to the recovery process of the ill relatives, further fuelling the burden experienced by caregivers (Shifiona et al., 2019). The study also found that health professionals do not provide information to caregivers and their ill relatives on respective mental illnesses and that both caregivers and ill relatives are reluctant to seek professional help in understanding and management of mental illnesses. Hence, the study proposed a collaborative effort between caregivers, ill relatives and health workers in tackling the mental health challenges, as well as positive communication between the trio, and community-based mental health services to reduce the barriers preventing access to mental health services (Shifiona et al., 2019). Furthermore, Dhaka et al. (2017) suggested that more be done in sub-Sahara Africa in terms of providing psycho-education on a larger scale but also accessibility of the mental health services.

2.4 THEORETICAL FRAMEWORK

According to Lippi (2016) and Kamal (2014), research investigating the implications of mental illnesses has only zoomed in on the individuals diagnosed with schizophrenia and rarely paid attention to the implications on family caregivers of these individuals. Hence, current treatment methods and interventions are primarily focused on individuals with schizophrenia excluding the caregivers (Kamal, 2014). This background informed the direction of this present study because the study sheds light on the lived experiences of caregivers with the purpose to better understand the dynamics of caregiving as it unfolds. The application of the family systems theory framework is suitable for this present study because the theory's baseline is to understand entire family dynamics as it occurs in family settings.

According to Bowen (as cited in Bregman & White, 2011), family systems theory came about in an attempt to understand human behaviour because of the notion that human beings are *emotionally interdependent*. *Emotional interdependence* is explained as a process in which people in close relationships whether parent-child dyad, couples or simply family members transmit emotions, actions and thoughts over time towards each other continuously (Sels et al., 2016). The theory further posits that as human beings we affect each other's feelings, cognitions, behaviours, choices and moods. To expand on interdependence functioning of family, Friedman (as cited in Cox, 2007) postulates that each family member assumes specific roles in the functioning of the family unit, therefore what affects one person of the family is likely to affect the rest.

Family units are perceived to be fundamental because they facilitate the occurrence of *emotional process*es within the family system. *Emotional process* comprises the subjective, physical and psychological experiences and is explained as the human ability to manage stressful life events and other life-threatening situations (Rachman, as cited in Howells, 2013). When people can successfully absorb the mentioned emotional challenges, the emotional dysfunction lessens in other areas of their lives because people can move past these experiences and in worse cases can accept situations they cannot solve. However, when people are no longer able to resolve the emotional disturbances or sustain balance (homeostasis), which is the case for most schizophrenia caregivers according to Kamal (2014), the disturbances bleed over into other areas of the caregivers' lives such as their employment and social lives and can consequently cause dysfunction in their overall health (Howells, 2013). For instance, the presence of mental illness in caregivers' health could affect their daily functioning of their caregiving. As illustrated in the literature, the emotional distress presented itself among caregivers of individuals with schizophrenia, firstly, by comprising the caregivers' physical and psychological health because of the stress correlated to caregiving (Milliken, 2001). Secondly, emotional distress was evident when caregivers either lost or had to give up their employment due to the demanding tasks of caregiving, which inadvertently affected the entire family units financially. Lastly, the emotional distress occurred when caregivers either forfeited their social relations voluntarily or involuntarily because of the responsibilities and challenges attached to the caregiving role (Kamal, 2014; Iseseo et al., 2016). Bowen's perspective of *emotional process* (as cited in Haefner, 2014, p. 836) explains the process as *societal regression* or *societal emotional process* in which family members experience more chronic and sustained anxiety, and regresses to a lower level of functioning. Meaning schizophrenia impacts the relationship of all other members within family units.

Hence, exploration of *family units* as a whole in its entirety for this present study is fundamental because family members are the main caregivers of individuals with schizophrenia as shown in the literature provided. Therefore, they are likely to carry additional responsibilities of their ill relatives when these individuals become mentally and physically unstable because of the illness (Kamal, 2014). Since emotions are transferable among people; the possibility exists that caregivers could transfer their emotions to their ill relatives in their role of providing support and protection. However, the transference of emotions does not support the earlier position of Bowen (as cited in Bregman & White 2011, p. 16-18) and Frieda Fromm-Reichmann (as cited in Johnston, 2013) who posit that schizophrenia was a causality of anxious mothers or dysfunctional family dynamics. Rather, taking care of caregivers' needs improves the prognosis of people with schizophrenia (De Sousa et al., 2012; Purba, 2017). Additionally, Quesada (1983) stresses that the investigation of families as whole units involves looking at them as integrated systems in which individuals cannot exist in isolation to the units because "the identity of the whole unit seems to be more than and different from the sum of its own parts" (p. 40). Inferring that, family dynamics cannot be understood by only studying individuals in the unit because the interactions and changes that occur in one person ultimately affect everyone else in the family unit.

In understanding family dynamics as per Bowen's family systems' theory, the current study will glean from the *emotional process* concept, the *circular causality* concept that is embedded in wholeness, as well as interrelatedness and *emotional interdependence* (Kamal, 2014; Quesada, 1983). These concepts assert that family dynamics unfold in a non-linear manner and that there is no beginning and end to the complexities of emotional process as it unfolds in family settings because of the interdependence among family systems. The conceptualisation of interdependence is that people's behaviour in a family setting can be influenced by other members of the family and vice versa, making this process reciprocal or circular. Circular causality in family systems is further maintained by the feedback loops that occur through common interactions within the systems and are relived through the other parts of the system (Quesada, 1983)

CHAPTER 3

RESEARCH METHODOLOGY

3.0 Introduction

This chapter covers the research design and methods employed in conducting the study, including the method of analysis and ethical considerations.

3.1 Research Design and Research Methods

A research design is the plan to answer the research questions with the strategies and methods used for data collection and analysis (Creswell, 2009). Research methods are various procedures and techniques actively carried out step by step to implement that plan; such as sampling, collection of data, data analysis and reporting of findings (Creswell, 2009). In a nutshell, research design and research methods refer to the “what and how” of the research respectively (Gelo, 2012). The present study is designed as an explorative study with a qualitative lens as a method of inquiry. The researcher is interested in gaining an in-depth understanding of the personal experiences of the caregivers of individuals with schizophrenia, a phenomenon that has not yet been formally explored in the Namibian context.

3.1.1 Qualitative Method

According to Bryman (2012), qualitative research is a multi-dimensional approach that embodies spoken and written words, as well as people’s experiences and subjective views. The approach readily utilises direct interviews and observations, particularly, when dealing with sensitive topics to capture the experiences of the participants (Creswell, 2009). Important to note is that the natural setting (suitable location for interviewee) in which the interview process takes place influences the research process and outcome; hence, thorough preparation of fieldwork is critical to minimise disruption. The preparation can involve familiarising oneself with the interview tool or ensuring that the interview space is conducive.

One benefit attributed to qualitative research with the explorative approach is the use of open-ended questions and probing (Mack et al., 2005). These elements allow participants to answer research questions in their own words instead of choosing from a set of answers provided and also give them opportunity to elaborate and clarify their answers. When participants have freedom in the interview process, research produces rich and in-depth data that is meaningful and specific to the participants' experiences and offers the researcher the opportunity to experience the depth and authenticity of the methodology and the participants (Mack et al., 2005). However, qualitative research is not completely value-free because the researcher's own subjectivity is inevitable in the interpretation process (Willig, 2013).

Additionally, conducting research in natural settings provides comfortability and privacy for the participants (Bryman, 2012), which in turn fosters rapport building between the participants and the researchers. Because researchers are likely to enter personal spaces of the participants to gather information, rapport building is essential to establish early in the research process to enable trust between the participants and researchers (Dickson-Swift et al., 2008). Rapport building is defined as a progress in which the researchers establish relationships with the participants that promote disclosure to the researchers.

Often, the stories or experiences shared by the participants are sensitive therefore, trust is important in this dyad relationship, especially, from the participants' perspective. The researchers must protect and assure the participants that whatever content shared will be treated with confidentiality and only used for the intended purpose (Horn et al., 2011). According to Aljazzaf et al. (2010), trust is a process where one party willingly relinquishes their power to control what they disclose to the other without fear of being exploited or the truth be omitted by the recipient. In the case of this present study, the participants' vulnerability to share their experiences of living with people with schizophrenia to the researcher should be valued and protected.

Another benefit of qualitative research is the flexibility it provides in face-to-face interviews although the interview process might be time-consuming (Mack et al., 2005). For this current study, the flexibility was applied by considering the participants' language abilities to ensure inclusivity because of the diverse ethnic groups that were represented in the study. Hence, participants seemed comfortable in expressing themselves because they had the option to either express themselves in their vernacular or preferred language. This, in turn, provided rich data as clarification was provided whenever there was uncertainty. In contrast, quantitative research rarely provides flexibility and inclusivity because the research is predominantly survey-based using fixed questions (Mack et al., 2005). Quantitative methodology is used when researchers wishes to save time and cost, and the methodology often lacks the human element (subjective views) and leaves no room for maneuvering if anything needs to be changed.

3.1.2 Exploratory Design

Dudovski (2016) states that exploratory research concerns itself with tapping into specific areas of the research that has previously not been investigated, therefore, is bound to produce new insight. This research employed this design specifically to discover and study the lived experiences of caregivers of individuals diagnosed with schizophrenia in Windhoek.

3.2 Population

Research population is defined as a group of people with similar characteristics that meet the criteria of the study from which only a certain number of people are selected (Asiamah et al., 2017). The population for the present study consisted of caregivers of out-patient and in-patient individuals diagnosed with schizophrenia in Windhoek. Both males and females above the age of 21 years were considered. Due to limited research on mental health in Namibia, more so on schizophrenia, the availability of empirical data on statistics of schizophrenia is non-existent. However, as communicated in person by senior registered nurses Nkolonga and Kazarako (personal communication March 19, 2019), at the Mental Health Unit Windhoek Central Hospital, an annual estimate of 4044 schizophrenia cases was reported from October 2018 to February 2019. Schizophrenia was ranked monthly among the top three disorders with cases varying between 224 and 337 intakes at the Windhoek Central Hospital’s Mental Health Unit.

3.3 Sample and Sampling Technique

Sampling is done to eliminate the impracticality of working with a large population, as such, a sample that is a smaller group of people representing the population is selected

(Creswell, 2009). Participants for this study were selected using a non-probability purposive sampling strategy. Purposive sampling is a technique that selects participants based on their characteristics, which are relevant to the study, and are likely to answer the research questions (Bryman, 2012). The following inclusion and exclusion criteria were employed.

A sampling grid, using age and sex as variables were employed as a criterion for the selection of participants. This included female and male caregivers above the age of 21 years. Although, the age of the majority is 18 years in the Namibian context, as per the *Child Care Protection Act 3 of 2015* (Government Gazette of the Republic of Namibia, 2015); neuroscientist, Yurgelun–Todd (2007) asserts that psychologically such persons may not be fully developed because their reasoning and decision making abilities are not yet matured. Hence, age 21 was chosen for this present study, as this age group is psychologically more mature. As a result, they are inclined to cope better with emotionally triggering situations.

Additionally, the out-patients were supposed to be in a remission, meaning that they were most likely not experiencing psychosis at the time of the interview because they were on medication. To ensure that the patients were in a remission state, the researcher carefully investigated the record files of the patients with the assistance of the psychiatry nurses on duty. Thus, only patients' files that indicated diagnosis of schizophrenia with "remission" status were selected and only caregiver participants who were willing to participate in the study were selected. This arrangement was purposefully designed to ensure that at the time of the interviews, the caregiver participants' well-being as well as the patient's and the researcher were protected because the majority of the interviews took place at the participants' homes were patients resided. Also, the arrangement was important to ensure that the facilitation of the research process was smooth and as natural as possible without any hindrances. If patients were experiencing psychosis at the time of the interviews, such patients were already hospitalised prior to the interview date. This was the case for in-patient patients whose caregivers were interviewed for this present study.

In total, eight participants were sampled, four in-patient caregivers and four out-patient caregivers and only one caregiver per family was interviewed. However, there was a case where two family members were identified as primary caregivers making the total interviews nine. Mack et al. (2005) and Creswell (2009) assert that qualitative research relies on small sample size because of the rich data it produces and that data saturation can be reached with a small sample. Thus, this sample size was deemed adequate for this present study. Previous studies conducted on this topic utilised a sample size of six participants (Evans, 2009; Kamal, 2014). According to Bowen (2008), data saturation is a process in which researchers exhaust the data until no new information or themes occur from the interviews conducted.

3.4 Procedure

A year in advance of the study, the researcher addressed a letter (*see Appendix B*) to the Ministry of Health and Social Services (MoHSS) research department, via the Permanent Secretary's Office to request permission to conduct the intended research at the Mental Health Unit of the Windhoek Central Hospital. Additionally, the researcher liaised with the senior nurses of the Mental Health Unit to introduce herself and to build rapport (Dickson-Swift et al., 2008) with the nurses because the researcher needed the assistance and guidance of the nurses, and also to notify the nurses of the study because the Mental Health Unit of the hospital was identified as the data collection site by the researcher. Previous studies that have conducted similar studies also identified various mental health facilities, such as psychiatric hospitals, community mental health clinics and volunteer organisations as their places of sample selection (Evans, 2009; Kamal, 2014; Nxumalo & Mchunu 2017; Suryani, 2015).

Secondly, the researcher needed familiarisation with the hospital setting and the staff, especially the nursing staff as their assistance was instrumental in the identification of the patients. Senior nurses already had established relationships with patients diagnosed with schizophrenia that were on treatment. As a result, they were able to guide the researcher on the schedule for out-patients and in-patients and the procedure for collecting data at the facility. This guidance inadvertently helped in the smooth operation of the data collection. The success of the data collection was crucial as it involved people's personal experiences and views that might be sensitive (Mack et al., 2005).

To reach out-patient caregivers the researcher was advised by the nurses to visit the hospital during the designated out-patient days, which were Mondays and Thursdays. The researcher had the opportunity to engage in-person with some patients that were able to identify their primary caregivers. Permission to engage with patients was granted verbally by the nurses on duty as well as assisting in the identification of the patients. Since the researcher is also a student psychologist, the researcher was able to gage patients' state of mind and only engage patients who seemed clinically sound according to the researcher's observation. Moreover, the medical records provided by the nurses ultimately verified the patients' clinical state. Additionally, to secure more out-patient caregivers the researcher retrieved next of kin information from the patients’ medical files. Again, having obtained permission from the staff the researcher contacted the respective individuals telephonically to inquire and verify the relationship status between them and the patients. In most cases, the next of kin were eventually the primary caregivers.

In selecting caregiver’s of schizophrenia patients who were hospitalised, the nurses from different wards, including male and female wards, provided the researcher with caregivers’ information. Caregivers were contacted telephonically to verify their respective roles in the patients’ lives. The next of kin who were recorded on the files of the in-patients were in most cases the primary caregivers of the in-patients. However, when there was uncertainty of who the main caregivers were, the persons listed as the next of kin in the file referred the researcher to the primary caregivers.

Lastly, even though basic English was a prerequisite for the interview process, most interviews were conducted in Afrikaans and Khoe-khoegowab. This was because the population from which the sample size was drawn involved various ethnic groups. As much as the researcher aimed to only select those with proficiency in English, language barrier became a challenge on the ground because most participants were not competent in the English language. Prospective participants for this present study were either fluent, comfortable or preferred Afrikaans or their local language as opposed to English.

Afrikaans was popular especially among the mature citizens. From the eight participants those who were above the age of 51 were more comfortable or preferred Afrikaans or their ethnic language as indicated in *Table 3.1* below. Since the researcher is a Damara by ethnic association and is fluent in both Khoe-khoegowab and Afrikaans, most interviews were conducted in those two languages. From the nine interviews, five interviews were conducted in Afrikaans, two interviews in Khoe-khoegowab and two in the English language. [1]

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[1] **Footnote:**

The perceived lack of proficiency in the English language among the participants could perhaps be attributed to the socio-political history of the country. Namibia is a former colony of the South African regime and Afrikaans was deemed as the official language during that period (Baker, n.d). The English language only came to the fore post-independence. During, the apartheid regime, people were stratified along the lines of ethnicity, besides, limited exposure to formal education (Baker, n.d). Therefore, they predominantly spoke only their local languages within their groups or Afrikaans when they engaged with other groups or with the colonisers. Afrikaans was also the official language and medium of instruction during the apartheid stage.

Table 3.3 Participants and their Demographics

Participant	Sex	Age	Ethnicity	Home language	Education	Occupation	Relation to patient	Patient		
								Sex	**Age**	**In/Out**
P1	M	64	Baster	Afrikaans	Std. 5	Pensioner	Father	M	30	Out
P2	F	35	Baster	Afrikaans	Gr 10	Unemployed	Sister	M	30	Out
P3	F	59	Afrikaner	Afrikaans	Degree	Business-woman	Brother	M	57	Out
P4	M	25	Ovambo	Oshiwambo	Gr 12	Payroll Assistant	Sister	F	38	In
P5	F	51	Damara	Khoe-khoegowab	Std. 3	Domestic worker	Spouse	M	52	Out
P6	F	58	Damara	Khoe-khoegowab	Std. 5	Domestic worker	Mother	M	39	Out
P7	F	26	Herero	Otjiherero	Gr 10	Admin Assistant (part-time)	Sister	F	37	In
P8	M	55	Herero	Otjiherero	None	Unemployed	Cousin	M	60	In
P9	F	59	Herero	Otjiherero	Gr 10	Unemployed	Mother	M	20	In

Table 3.3 above shows the demographic information of each participant.

3.5 Data Collection

Data collection is a process in which the researcher gathers information from the participants, using specific instruments or tools that answer the research questions or speak to the objective of the study (Kabir, 2016). A few weeks before the actual interview process, the researcher received the approval letter (*see Appendix C*) from the MoHSS Research Department to conduct the research. This letter was then submitted to the management of the Mental Health Unit of the Windhoek Central Hospital. Upon receiving the verbal approval from the head of the Mental Health Unit, the researcher visited the Mental Health Unit of Windhoek Central Hospital on the respective dates appointed for out-patients (Mondays and Thursdays) and in-patients (Tuesdays and Fridays). The researcher handed out information (*see Appendix E*) letters and explained the purpose of the study to the caregivers that the researcher encountered at the Mental Health Unit as well as patients that appeared clinically stable and were able to present the recruitment letter to their respective caregivers. Caregivers that were interested in the study on a voluntarily basis were chosen for the study.

Additionally, the researcher with the assistance of the nurses on duty identified potential caregivers from the medical records of the patients. The lists of contacts from the medical records were caregivers who the researcher did not have the opportunity to meet at the facility. These individuals were contacted telephonically and informed about the objective of the study. Interested and willing parties who agreed to participate in the study communicated their availability and choice of location to the researcher telephonically. As postulated by Dickson-Swift et al. (2008), many participants preferred their homes as a location for interviews to be conducted. From the eight interviews, only three interviews were conducted at alternative places suggested by the participants, such as an office space, researcher's home and the Mental Health Unit of the Windhoek Central Hospital.

Semi-structured interviews are similar to in-depth conversations. Since the research was concerned with understanding caregivers' experiences in taking care of individuals with schizophrenia, the gathering of information occurred by talking with and observing the participants' non-verbal cues (Creswell, 2009). A self-made semi-structured interview guide that predominantly consisted of open-ended questions was employed to facilitate the data collection process (Bryman, 2012). The guide was well suited for this research as it provided in-depth information. Simultaneously, it offered an opportunity to the participants to frame their experience as they saw fit and to mention what they felt was worth revealing (Creswell, 2009). Furthermore, the interview structure created the opportunity for probing, which in turn, generated new information. This method provided an in-depth understanding of the participants' lived experiences and perceptions in caring for individuals with schizophrenia. .

To ensure that all the information shared by the participants was captured, the interviews were conducted by using audio recordings with the informed consent and permission of the participants (Cresswell, 2009). At the same time the researcher was also taking notes. According to Mack et al. (2005) written notes are important because they provide a back-up to the audio recordings. In addition to taking notes, recoding of participants' behaviour is crucial as it captures the essence and nuances of the experiences of participants that may not be verbally communicated. The researcher did this by observing the participants' behaviour and reactions throughout the interview process. Once the researcher completed the interviews the audio recordings were transcribed. Bailey (2008) terms transcribing as a technical process in which the researcher types out the audio recordings word for word (verbatim) as mentioned by the participants. This process is central to data analysis. To further cement the validity of the interview guide and to measure its comprehensiveness the researcher used the first two interviews as pilot interviews meaning that in total eleven participants were interviewed.

3.5.1 Individual Interviews

On the scheduled day of each interview, the researcher called the participants in advanced to confirm the appointment. Upon arrival at the preferred location, the researcher introduced herself to the participants. Thereafter, the researcher explained in detail the purpose of the study as outlined in the recruitment letter. Also, informed consent (*see Appendix D*) was discussed in conjunction with privacy and confidentiality as well as the use of audio recordings. Participants were granted an opportunity to ask questions or to clarify any issues about the study to eliminate any uncertainty or fears that might interfere with the interview process. Once the informed consent was obtained verbally and in writing the researcher proceeded with the interview process. The interviews varied between one hour and two hours depending on the context and content giving by the participants.

These face-to-face interviews were carried out to capture the participants' unique experiences and perspectives. Participants were asked overall questions on their experiences in looking after their relatives with schizophrenia and how the experience may have impacted them. The questions also explored their emotional and financial challenges as well as their coping styles and availability of supports systems. Questions covered the needs the participants may have identified in the process of caregiving, which encompasses personal and service provider based needs.

After each interview, debriefing sessions – an opportunity to discuss what unfolded in the interview process - was held to ascertain the emotional state of the participants. Many participants reported that they appreciated the interview process because they had the opportunity to express their concerns and struggles. Additionally, the researcher allocated time for participants to ask questions or get clarity on issues relating to the study or to answer questions on schizophrenia that participants wanted to know. Since the researcher is trained in mental health and is interested in schizophrenia, the researcher was confident in sharing knowledge on schizophrenia that was pertinent to the participants.

In case the participants might require further counselling services, the researcher directed them to the Lifeline/ChildLine and Mental Health Unit at Windhoek Central Hospital as these facilities offer free counselling services. The researcher thanked the participants for their time, effort and sharing their sensitive experience with the researcher. Transport fees were covered by the researcher when needed; therefore, participants did not incur any cost during this study.

3.6 Data Analysis

The data analysis for this study employed a thematic analysis. Thematic analysis is generally concerned with identifying, analysing and reporting on patterns or themes within the data; while organising data minimally and describing it in a rich detail (Braun & Clarke, 2006). In a nutshell, the objective of the method is to purposely find repeated themes of meaning across the data. This analysis method is flexible and is not restricted to a particular theoretical framework or methodology in its application. Nevertheless, Braun and Clarke (2006) encourage a collaborative use of theory and methodology in the application of thematic analysis.

In conjunction, a descriptive (semantic) approach was used in the manner the data was analysed (Braun & Clarke, 2006; Maguire & Delahunt, 2017). This means the researcher simply reported on the themes as they occurred in the data or as they reflected the participants' realities. The researcher's objective was to highlight the essential or main themes. Juxtaposing this aspect is the latent approach that delves deeper because the approach is concerned with constructing meaning through the language use of the participants. However, the latter approach was not the interest of this present research. The former approach is often used when the topics investigated are understudied, or participants' opinions on the subject matter are unknown (Braun & Clarke 2006). This approach is relevant to this current study because the subject of schizophrenia is understudied in the Namibian context and participants' opinions on the subject matter at the time of conducting the research were unknown. However, this does not negate the richness that could be derived from descriptive analysis as the information is analysed.

Furthermore, with the collection of data and analysis the researcher gleaned from both the deductive and inductive processes (Kamal, 2014). In the deductive process, the researcher has a prior theory or working assumptions of how the data should be gathered or analysed, whereas, in an inductive process the data determines the theory or the working assumptions (Braun & Clarke, 2006; Kamal, 2014; Maguire & Delahunt, 2017). For the data collection process, the researcher in this present study applied a deductive route, which inadvertently identified a specific population for the study. However, in analysing the data an inductive lens was applied. The process allowed the data to direct the analysis thus nullifying any preconceived notions the researcher may have had prior about the subject matter (Braun & Clarke, 2006). As a result, original first-hand and context related knowledge was generated as participants' own voices were captured.

The following thematic steps according to Braun and Clarke (2006) were followed in analysing the verbatim transcriptions of eight participants.

Firstly, the researcher familiarised herself with the information by reading and re-reading the verbatim transcripts that the researcher transcribed herself. This process provided immersion of the data and the researcher could actively identify themes and sought for meaning in the transcribed information. The researcher made notes of information that seemed interesting and spoke to the research questions.

The researcher subsequently highlighted ideas that were similar or were contrasting in different colours as they constitute coding. Coding as part of the analysis only identifies similar segments of the data but is not the actual theme. Coding is the building block of the themes. Furthermore, this data was categorised in meaningful groups (Braun & Clarke, 2006).

Thirdly, the process involved identifying themes. The researcher actively constructed potential themes from clustered codes that were assimilated in the prior phase. Braun and Clarke (2006), posit that this process is active as themes are generated and not discovered. During the data analysis process, the researcher asked the following questions "*Is this a theme?", "Does it tell me something useful?", "What does it include and exclude?", "Is the theme thin or thick" and "Is it coherent"* (Castleberry & Nolen, 2018, p. 810).

Fourthly, the themes were reviewed. Important to this process is for themes to be clear without overlapping and to connect to the data. Thereafter, the themes were defined and named. This process entails refining themes to have an overarching theme which comprises sub-themes (Braun & Clarke, 2006). Finally, the researcher produced a report as presented in the next chapter of the thesis.

3.7 Validity of Research Data

Validity is the process in which the researcher must ascertain the accuracy and truthfulness in scientific findings (Brink, 1993; Creswell, 2009). Obtaining validity within qualitative research may be a challenge because of the subjective nature of the approach that is based on people's beliefs, experiences and perspectives (Brink, 1993) as opposed to quantitative study that relies on statistical methods. Therefore, the influences of the biases from the researcher, the participants, the setting or context of the study, as well as procedures employed in data collection and analysis should be considered when using qualitative research (Creswell, 2009).

To counter the validity argument of the positivists approach and to solidify scientific soundness of qualitative research through trustworthiness, Guba constructed specific measures such as credibility, transferability, dependability and confirmability (Shenton, 2004). Credibility speaks to the accuracy of the study – how much the study truly reflects the phenomenon being investigated. In asserting credibility, the researcher employed several techniques.

Firstly, the researcher gleaned from previous studies with similar topics and data collection methods (Shenton, 2004). Purposive sampling method was specifically used to identify the caregivers at the Mental Health Care Centre which is part of Windhoek Central Hospital.

Secondly, the researcher familiarised herself with the hospital setting which was the avenue for sampling. Also, the researcher interacted personally or telephonically with potential participants often, whether it was to introduce the study or to confirm appointments which created a pathway for rapport building- the foundation for the trust needed in sensitive studies (Mack et al., 2005; Shenton, 2004).

Thirdly, to ensure honest answers, which is an integral aspect in the validity of the research, only participants that were informed about the study and willingly participated knowing that they could withdraw at any time were interviewed (Shenton, 2004). During the interview process the researcher checked in randomly throughout the interview process to ascertain participant's stance on the study.

Fourthly, triangulation was established through the application of multiple data sources to provide a coherent explanation for patterns (Creswell, 2009; Kamal, 2014; Shenton, 2004). This included interviews, field notes and audio recordings.

Furthermore, to obtain transferability – the process that involves whether the study can be applied in a different context (Shenton, 2004); the researcher clearly defined the parameters of the study. In other words, the study involved only the caregivers' experiences with people diagnosed with schizophrenia that lived in Windhoek. Therefore, the findings of this study cannot be generalised to the rest of the country.

According to Shenton (2004), the dependability of the study is assured by reporting the research process in detail for the research to be replicable. This objective was achieved in this study as the researcher provided a thorough step-by-step process in the methodology section, including the theoretical underpinnings.

To warrant confirmability for the study, the researcher relied on the use of reflexivity and audit trail (Kamal, 2014; Shenton, 2004). An audit trail is defined as a process that allows the researcher to trace the course of the research step-by-step through the decisions made and methods described (Shenton, 2004, p. 72). In support, the researcher earlier provided a thorough explanation of the utilisation of the inductive process (data-driven) and deductive process (theory-driven) under the data analysis section. This attempt was to manage possible bias the researcher may have as a researcher and as a psychologist, and to allow the data to produce objective findings.

Also, the researcher was very cognisant of her position as a psychologist and was careful not to assume that she understood what the participants meant in their communication. Hence, the researcher was reflective and asked for clarity on several occasions. To further try and minimise therapist biases and to avoid stepping back into the therapy role, the use of open-ended questions were encouraged to allow the participants to reveal their own experiences (Kamal, 2014). Instead of asking questions relating to feelings, "*how does taking care of your relative make you feel*?" the researcher rather focused on experiences, "*tell me how taking care of your relative has impacted your life?*". This distinction in questions was important to get the information related to the research questions.

3.8 Ethical Considerations

Research ethics is a fundamental aspect when conducting research. This is simply because in studies, such as this, human participation is involved and often vulnerable populations are at risk of exploitation whether intentionally or inadvertently (Mack et al., 2005). Hence, this study employed certain protective factors for the participants of this study.

In doing so, the following ethical protocol steps were adhered to. Before the commencement of the research, ethical clearance was sought and granted by the Research Ethics Committee of the University of Namibian (*see Appendix A*). Support documents, such as the interview guide (*see Appendix F*), informed consent (*see Appendix D*) and recruitment letter (*see Appendix E),* as well as request for permission letter to conduct the study from the MoHSS (*see Appendix B)* were attached. Also, the researcher ensured that approval was obtained from the MoHSS research committee (*see Appendix C*) and the management of the Mental Health Unit. This was compulsory as the Mental Health Unit was the appointed avenue for the sample, a department that is directed by the MoHSS.

The researcher obtained verbal and written consent from all the participants. To safeguard the privacy of the participants the researcher assured them anonymity and confidentiality. Anonymity is the process in which the researcher guaranteed the participants that their personal information obtained in the demographic section will not be divulged to third parties. Neither will the information shared during the interviews be linked to them in any way *(Guidelines on Anonymity*, 2017). Confidentiality was provided through maintaining clear boundaries in the information shared between the researcher and the participants – other participant’s information was not divulged even when there was similarity in the interviews (Mack et al., 2005). This was vital as Social Science researchers operate in a social context that involves conversations and information can easily and unintentionally be transferred from one participant to another in a conversation.

Furthermore, all the field notes including the transcripts and audio recordings will be kept safe in a cabinet strictly accessible only by the researcher. This is to avoid breaching of confidentiality and privacy.

CHAPTER 4

RESEARCH FINDINGS AND DISCUSSIONS

4.0 Introduction

This chapter presents the data as gathered and analysed from the lived experiences of caregivers of relatives diagnosed with schizophrenia. The overall objective of this study is to understand the caregivers' perspectives, their needs, their coping mechanisms, and the disparity that exists between mental health providers and caregivers in terms of the services provided. The chapter gives a brief background of the participants as well as presents the findings and discussion of the results of this study.

Thematic analysis was applied as a method of analysis for each interview to draw out the emerging themes. The themes presented in the study, were according to the relevance of the objectives and research questions of the study. The caregivers' demographic information and the emerging themes are presented in a table form.

4.1 Description of Participants

Eight family units were selected for an interview but one family consisted of two primary caregivers. So, in total nine caregivers were interviewed. However, note that in the outline of the interviews, participant one and participant two's narratives will be recorded separately even though they are representing one family unit. Interestingly, all caregivers were situated in nuclear family settings. From the nine caregivers, four were siblings to the ill relatives, four were parents and one was a partner. The participants' ages ranged between 25 years and 64 years. For anonymity and confidentiality purposes, participants' names were omitted.

Participant 1 and Participant 2 – Participants consist of two primary caregivers. The father (caregiver) and the sister (caregiver) who are the main caregivers, and the sister's partner, their three children as well as the patient (son) live together. The patient's mother passed on many years ago. The father is a pensioner, the sister is unemployed and only her partner is employed. The main income for the household is the father's pension and the disability grant of the patient. The participants have their own residence in Khomasdal where the interview was conducted. According to the caregivers, the patient was a normal functioning bright learner throughout his school career and passed Grade 12 exceptionally well and had dreams of pursuing a university career before the illness began. He was also an active member of a prominent choir group and toured nationally and internationally with the group. His illness not only placed the father and sister in a permanent caregiving role, which they have occupied for the past 11 years but also, shattered the family's dreams of enjoying a better quality of life.

Participant 3 – The household consists of the caregiver, her husband, brother (patient) and the live-in house help. The participant has two adult sons that live on their own with their families. According to the participant, she and the brother come from a troubled childhood background. The parents divorced early in their childhood and the father died early on due to suicide. The brother was a highly intelligent and ambitious person that was employed in a few high-level positions, such as being advocate. However, the brother lost everything he once owned due to his illness and has no income now, however, recently applied for the disabled people's grant. The brother has had the illness for almost 30 years. Although the mother is alive, the participant took on the caregiver role as she can provide better care for her brother, especially, since she almost lost her brother a few years ago. The participant has assumed this role periodically for the past 11 years. The participant is self-employed and availed herself during her work hours for the interview.

Participant 4 – A 25 year old participant was the third interviewee. The caregiver has looked after his older sister for the past two years and shares a rented space in Katutura with her. The parents are pensioners who are based in the northern part of the country. Although the participant has other older siblings, he took on the caring responsibility because he is the only sibling based in Windhoek currently and since his sister refuses to return to the north the onus is on him to care for her. The sister was previously cared for by an uncle, but due to the complex nature of the illness the uncle passed on the responsibility to the brother. According to the brother, the sister is employable, but she rarely lasts in a job because of her illness. At the time of the interview, the patient was institutionalised for a week at the Windhoek Mental Health Unit. This interview was conducted at the researcher's residence.

Participant 5 – The participant lives in a shack house which she owns in an informal settlement. The interview was conducted at the participant's house. She shares the house with her partner (patient), their daughter and her boyfriend as well two toddler grandchildren. The participant's first born son was hit and killed by a car a few years ago near the house. Her second born son whom she shares with her partner lives mostly on the streets as he also presents with the similar illness as the father. The participant is the main breadwinner of the household and although her partner receives his disability grant her domestic work income is what sustains the family. The participant and her partner have been together for the past 27 years, however, the last 14 years has become unbearable for the participant and other members of the household since the illness of the partner has started. According to the participant, there are constant verbal fights in the house that are caused by the partner because of his illness.

Participant 6 – The participant has two children, a son (patient) who is the firstborn and her daughter that is a mother to a young girl. The family shares a one bedroom flat in Katutura, which her employer is helping her to pay. According to the participant, since they have moved out from a family house when her son was still in primary school they have only been renting rooms for most of her life and owning a house was her greatest concern. The son was diagnosed with schizophrenia 11 years ago when life became significantly challenging for all of them. When he was a normal functioning person prior to the diagnosis, he was a self-employed disk jockey (DJ) and also worked full-time at a pharmacy. Since his illness he could no longer be employed fulltime. Although, he gets a disability grant, the mother is the main provider and often works seven days a week to provide for the family. The interview was conducted at the participant's home.

Participant 7 – The participant lives in the mother's house with her daughter, mother, and younger sister as well as the older sister's (patient) infant in the main house. The brother stays in a shack in the backyard of the house. At the time of the interview, which took place at the residence of the participant, the sister was admitted for the third time at the Mental Health Unit. The sister, a mother of five children, lives at a village with her children. However, since the onset of the illness that happened three months after she gave birth to her five month old baby, the sister has relocated to Windhoek for medical treatment and has been living with her family for the past 3 months. Although the brother is the only person currently employed full-time he has his own household. The mother's pension grant and the income she makes from renting shack rooms to tenants is the main income for the household. The participant is employed part-time but on a temporarily basis and her younger sister is still in school. Also, the mother suffers from a similar psychiatric illness as the daughter who is hospitalised.

Participant 8 – The participant owns a house with his wife, and lives with his brother (patient) and nine children. The patient is believed to have been abnormal or mentally unstable since he was a young child. As a result, he never attended school and grew up with his grandmother on the farm. He was close to his grandmother and was helpful on the farm but as he grew older he wandered off and lived most of his life on the streets. The participant shared that the brother's maternal sister also suffers from a similar illness. As a result of his illness, the patient was entangled in a legal situation with the police and was in holding cells for a year but was pardoned because of his illness and was released into the care of the participant. The participant has been in the caregiver role for the past two years and stated that the brother's condition seems to have improved since he has been staying with him. However, the brother still experiences occasional anger outbursts. Because of that, the brother was admitted at the Mental Health Unit for a week at the time of the interview, and was supposed to stay for another week. Upon his discharge, the family arranged for the patient to move to the farm permanently. The patient is on disability grant. This interview was conducted at the Mental Health Unit on a bench as the participant was there to visit his brother.

Participant 9 – The participant (mother) shares a rented room in a family house with her son (patient). She is currently unemployed and lives off donations from neighbours and church people. The son has not yet been registered for the disability grant because the mother fears that an income may exacerbate the son's illness as he is believed to be using illegal drugs. At the time of the interview the son was admitted at the Mental Health Unit for a week. The participant seemed disheartened by what happened to her son as she felt that the illness destroyed her beautiful, bright, and respectful son's life. The son was diagnosed with schizophrenia 16 months ago, and as a result had to shorten his school career. Even though the son historically was academically challenged since primary school, he was determined to complete his school career and improve their living condition. This interview was conducted at the participant's house.

Table 4.2 Themes and Sub-Themes:

Four Main Objectives of The Study	**Themes**	**Sub-Themes of Theme Categories**
4.2.1 Caregivers' Perspective and Knowledge of Schizophrenia	4.2.1.1 Diagnosis and Knowledge of Schizophrenia	• "In the Dark" • Socioeconomic Status Buys Privilege to Information
	4.2.1.2 Accessibility of Health Workers and Information	• No Information on Schizophrenia • Lack of Information • Feeling Excluded and Insignificant
	4.2.1.3 Schizophrenia as Conceptualised by Caregivers	• Understanding Schizophrenia as a Mental illness • No Understanding • Cultural and Traditional Beliefs
	4.2.1.4 Abnormal Behaviour Indicates the Onset of Schizophrenia	• Accused of Killing or Witchcraft • Confusion • Lack of Self-Care • Extreme Strange Behaviour
	4.2.1.5 Treatment of Schizophrenia	• Knowledge of Medication • Function of the Medication • Effectiveness of Medication • Non-Adherence to the Medication • Lifelong Illness

4.2.2 Caregivers’ Experiences in their Role as Carers	4.2.2.1 Assuming the Care Role	• Who will carry the Burden? • Self-taught caregiving
	4.2.2.2 Odd Behaviours make Caregiving Very Difficult	• Loss of Freedom and time
	4.2.2.3 Emotional Distress and Physiological Health	• Worry • Fear • Anger • Depression/Sadness • High Blood Pressure
	4.2.2.4 Financial Burden Associated with Caregiving	• “I do everything” • Unforeseen Cost • Future Financial Woes
	4.2.2.5 Lessons Learned	
4.2.3 Caregivers’ Ways of Coping and Support	4.2.3.1 Subjective coping	• “God is good” • Compassion, Acceptance, Love and Gratitude • Accommodating Ill Relatives’ Behaviour • “Just Coping”
	4.2.3.2 Objective Coping Styles	• “We cope”
	4.2.3.3 Lack of Social Support	• No One to Talk to • No Formal Support Groups • Lack of Awareness of Counselling Services
	4.2.3.4 Government Interventions	• Basic Needs • Community Health Centres

4.2.4 Caregivers’ Experiences with Service Providers	4.2.4.1 Difficulty Accessing Medication	
	4.2.4.2 Caregivers’ Needs from Health Workers	• Psycho-Education • One-on-One Communication • Inclusive language use
	4.2.4.3 Overall Service Experiences	• Inconsistency of Doctors • Unhygienic Environment • Positive Experiences

4.2 Research Findings and Discussion

4.2.1 Caregivers’ Perspective and Knowledge of Schizophrenia

According to Iseselo et al. (2016), being knowledgeable and having understanding about mental illnesses is crucial for patients and family caregivers because mental illnesses are often misunderstood and stigmatised in most societies, therefore, influencing help seeking behaviours and the treatment method. Sibiya et al. (2019) asserts that the harm caused by stigma around mental illnesses has dire consequences for the caregivers of people with mental illnesses. Although the participants in this present study did not specifically speak on stigma experienced, they shared having very little information and knowledge about schizophrenia, which resulted in them feeling, burdened and frustrated by their ill relatives condition. The following themes were extracted to give insight into the caregivers’ perspective on schizophrenia.

4.2.1.1 *Diagnosis and Knowledge on Schizophrenia*

In understanding any illness the diagnosis of an illness is crucial because the diagnosis informs the treatment method. Also, knowing the diagnosis could be helpful to caregivers as they could learn about the illness simply by knowing the name of the illness.

The majority of the mental illnesses classified in the *Diagnostic Statistical Manual (DSM)*, has mental illness names and are categorised along the lines of the spectrum they fall in. Mental health professionals, such as qualified psychologists and psychiatrists, who have gone through the required training, are familiar with the *DSM* because they are guided by the manual when giving the diagnosis to patients. Professionals are not only obliged to know and understand the diagnosis they give patients, but are responsible to explain the diagnosis in detail to the patients and to caregivers that are caring for people with chronic mental illnesses such as schizophrenia. Schizophrenia can incapacitate patients' cognitive, occupational and social functioning (Barlow & Durand, 2012), and since caregivers, between 50- 90%, are responsible for and live with relatives with schizophrenia, it makes sense to inform them of the diagnosis (Riley-McHugh et al., 2016). Despite these findings, participants in this current study did not know the diagnosis of their loved ones and felt that they were in the dark and had very little information on the illness. To support, the participant's standing on limited information, Rahmani et al. (2019) and Shamsaei et al. (2015) also found that caregivers in their studies felt overlooked by mental health professionals as they had limited information on schizophrenia. Participants in this study had the following to say when asked about the diagnosis.

- ***"In the Dark"***

Participant1: "*Maybe it's on the (health) passport…they don't tell us. That is why I am in the darkness".*

Participant 4: "*No. I don't know the name; those funny names…long names. But we all know that it's a mental illness and she sometimes needs attention from the psychiatrists or the doctors".*

Participant 5: "*No. I don't know…he is crazy…the man's head is sick. He is mental".*

Participant 7: "*So far, since I went and got her from Gobabis I don't know much about her illness. She doesn't live with us. The doctors were asking questions about her childhood and said that these things start from our childhood. Like she didn't grow up with her parents she was raised by her father's family and maybe these things affected her. But I think her brain is too fast according to what the doctors were saying".*

Participant 8: "*I don't know his illness name; I just know it's a mental illness -people who are not right in their minds. It's only now that I hear from you that there are different names"*.

Participant 9: *"Maybe they wrote in a file. I don't know"*.

From the above responses it is clear that six of the eight participants had no knowledge of the diagnosis. This finding coincides with the literature shared above that caregivers have limited knowledge of schizophrenia, which inadvertently would affect their caregiving process.

Participant 3 and 6 had the following to say:

Participant 3: "*I think its paranoid schizophrenia. Dr Schwindack diagnosed him 20 or 30 years ago"*.

Participant 6: "*Mmhh it's something called schizo….phrenia. He told me* (pointing to the son). *But I don't know what it is. He was diagnosed in 2008 by Dr Sieberhagen*".

An interesting observation from these two responses is that the above participants not only knew the names of their ill relatives' diagnoses although Participant 6 was not confident about what the diagnosis meant, but both participants had access to private psychiatrists at the time these diagnoses were given to their loved ones, meaning private psychiatrists afforded them knowledge. However, at the time of the interviews these relatives were treated at the state Mental Health Unit.

- ***Socioeconomic Status Buys Privilege to Information***

Perhaps one could infer that better socioeconomic status equates better information for participants. A comparative patient satisfaction study conducted in Pakistan between private and public hospitals found that private hospitals are not only providing better service, but are empathetic towards their clients, and doctors in these settings are well experienced and are sincerely invested in their clients (Irfan & Ijaz 2011). Participants 3 and 6 further elaborated on their knowledge on schizophrenia when asked who informed them of the illness.

Participant 3: "*Dr Schwindack explained to me that perhaps the illness could have been triggered by my father's death. My dad committed suicide. And after my dad's death both of us got into depression and I was put on anti-depressants. She said it can be hereditary but sometimes it can happen out of nowhere.*

She did explain to me a little bit that people with schizophrenia don't want to take medications and that there's going to be conflict around that. She told me that being in family environment is a good thing for him. She also mentioned that they are unmotivated so I must give him tasks to do and to tell him to do it".

Participant 6: "*Doctor asked me about our environment and said that sometimes environment can affect a person.*

I was almost convinced that it was as a result of the scar on his head, which happened during his birth. During his birth the doctors had to use forceps

> *to pull him out. The nurses at the Mental Health Unit told me that that could have caused his illness. But after speaking to Dr Sieberhagen I came to realise that people carry emotional burdens or suppress their emotions which can cause this illness. He is someone who doesn't like to express himself.*
>
> *Also he used to wander away from home. But Dr Sieberhagen said that we shouldn't stress about that and to not get police involve when he walks away from home. Rather we should be supportive towards him. These people respond to love*".

These responses confirm that indeed having enough money can buy you access to better information which was not the case for the other six participants as their relatives received their diagnoses from the state Mental Health Unit. Privilege to information no longer was the case for Participants 3 and 6 when their ill relatives transferred to the state services. They too were subjected to minimal information as the other six participants. This is indicated in the following theme.

4.2.1.2 *Accessibility of Health Workers and Information*

Participants in this study had limited contact if any with health professionals at the state Mental Health Unit. Therefore, they had inadequate information on schizophrenia. Participants expressed the following about their relations with the mental health workers.

- ***No Information***

Participant 1: "*The thing is when you get to the hospital then you only tell them about his behaviour at home. They will not tell you what his illness is. You are just* *supposed to say how he is at home. They just want to know if he smokes or drinks; that's all. No, it's just the tablets and injections they give. Then they write in the file about his follow-up. We don't have a clue as to what is going on. There is no information".*

Participant 8: "*I rarely speak to a doctor about Michael's illness, unless I bring him there and doctors want to know about his behaviour"*.

Participant 9: "*Doctors didn't tell me about Ephraim's illness…they only asked about his behaviour"*.

Participant 7: "*I haven't met with the doctor yet. Whenever I go there, the doctor is not there*".

The responses suggest that the relationships between health workers and caregivers are linear and structured; because health workers only seem to gather information without disseminating information to caregivers. Additionally, the lack of contact with health workers has caused frustration and sense of helplessness among participants in this present study. To bridge this gap Pejlert (2001) advocated for reciprocal relationships between Swedish caregivers and health workers in order to lessen the burden of caregivers.

Other studies have highlighted the health workers incompetence in providing information and psycho-education to caregivers (Caqueo-Urízar et al., 2017; Chen & Greenberg, 2004; Milliken, 2001; Pejlert, 2001; Sibiya et al., 2019). As a result, the majority of the family caregivers remains uneducated and lack sufficient training on the management of the people with schizophrenia (Pejlert, 2001; Sibiya et al., 2019).

- ***Insufficient Information***

Two participants noted that they only received some information.

Participant 4: "*This was the first time that I spoke to the doctor; usually my sister is the only one who speaks to the doctor. The doctor only explained to me about the medication".*

Participant 5: *"There are still things I would like to know…"*

- ***Feeling Excluded and Insignificant***

In addition, Participants 3 and 9 felt that health workers do not include or acknowledge them in the illness of their relatives even though they are the ones caring for the schizophrenia patients.

Participant 3: "*Tell me about the case and not just him! They ask him how he is doing and he just responds that he is well. Ask me! He lives with me! Because he is always good, doesn't matter what the issues are. When he cut off his toe nail it was also good. With that, whenever he said he is doing good I would ask him, 'Brother what normal person would cut off his finger and toe nail with a steak knife?' It's all that I would ask him, I would not debate*".

Participant 9: "*I want the doctors to involve me in every step of Ephraim's illness".*

Participants 1 and 6 felt that their voices were silenced or not significant enough when they raised concerns about their ill relatives' behaviour to the health workers. The participants felt that ill relatives were often untrue in their reporting of their behaviours to the health workers but the health workers did not pay attention to that.

Participant 1: "*When I bring him there, they will call him in and asked questions. I sit with him in the room and they ask him how he is. There are some days that he would say something and I would say something else– what he says is not true. Or if I give an answer then we end up fighting or arguing, but the doctors don't investigate that. They must follow the story, but they just write their things*".

Participant 6: "*... these people never tell the truth. They still drink when the doctors tell them not to, and when you go with them to the doctors they lie in front of you about their behaviour. Even last week Friday he was out drinking with his sister, and she got stabbed. He promised the doctors that he will not do it but he goes back to drinking. Whenever the doctor asks him how he is, he says that 'he is good' even when he is not good. If people don't love themselves they will do things that are hurtful to themselves*".

These responses coincide with other studies, which indicate that health workers are known to disregard the role of the caregivers in the lives of the ill relatives (Rahmani et al., 2019). In a South African study, caregivers stressed the need to be included by the health workers in the care plan of their ill relatives (Monyaloue et al., 2014). Trivedi (2002) asserts that the inclusion of caregivers in the care and support of ill individuals in India is beneficial because relapse rates have dropped significantly among people with schizophrenia. These studies suggest that the status of the relatives with schizophrenia could be improved if caregivers are better educated on the subject. The assumption is that the same could be true for Namibians.

4.2.1.3 *Schizophrenia as Conceptualised by Caregivers*

Participants in this present study come from diverse backgrounds – each one had their own understanding of the illness. Some participants understood that schizophrenia is a mental illness, whereas some felt it is the absence of medication, and others simply had no idea what it was.

- ***Understanding Schizophrenia as a Mental Illness***

Participant 4: "*This is a mental illness that he has*".

Participant 5: "*The nurses at the mental told me years ago about his condition*".

Participant 7: "*I know about the illness for years now. I understand it as a mental illness. I just accept that there are people with that illness*".

The above account of the participants' understanding of schizophrenia coincides with (Barlow & Durand, 2012) assertion that schizophrenia is indeed a mental illness. Additionally, the illness is listed as such in the *DSM-5* (APA, 2013).

Some participants understood schizophrenia as an illness in, which medication plays a significant role, suggesting that the two cannot be separated. This understanding is correct because psychotropic medication is crucial to the functioning of people with schizophrenia. When people default on their medication their functioning will be affected.

Participant 3: "*I noticed that if a person is not on medication that they become out of touch with reality*".

Participant 4: "*I think she was just supposed to take medication but since she's stubborn…you cannot keep on forcing her".*

The biomedical treatment of schizophrenia, which consists of antipsychotic medication helps to reduce, and manage the symptoms of the illness (Meyer & MacCabe, 2012). However, as evident in the above narratives, adherence to medication is not always guaranteed. Patel et al. (2014) note that between 34% and 73% of patients diagnosed with schizophrenia are likely to default on medication, which can result in relapse.

- ***No Understanding***

Some participants had no idea of what was happening to their relatives. Participant 1 found this lack of knowledge quite frustrating.

Participant 1: "*We don't actually understand his story…because one day he will say things that will make you wonder, but this young man…how does he come to these things? It's like he is in his own world. The type of things he says. You also wonder what it is with him. I just want to know what is happening with him…I don't know where I will get that answer from; from whom? And what has happened? The fact that I don't know what the story is…what the matter is with him is upsetting.*

Look…the thing is one doesn't know if he used drugs at some point. He was never someone that would be away from home, so that is also puzzling. And I see how people that use drugs look like, but they don't act like him. So somehow I don't understand what could have happened…

I must find out who it is…it must be that someone did something to him. He helped kids in this street a lot…with schoolwork. It's the children that he helped. Now they are working and he is as he is. He didn't do this to himself, something has happened to him".

Participant 2: "*Maybe it's the intelligence…he is very intelligent*".

Participant 7: "*The problem is I really don't understand her illness enough, but what I know is harassing her and stuff won't help anything. I think she needs more attention, and we need to be calm and support her in whatever she is sick*".

Similarly, a study conducted in northern Namibia indicated that caregivers had no understanding of mental illness because of their reluctance in reaching out for help from professionals (Shifiona et al., 2019). Lippi (2016) supports this argument, asserting that in addition to a lack of resources, which causes burden for caregivers; caregivers also fail to communicate their challenges to the health workers. Although this stance may be valid, numerous studies across the globe refute that notion as they postulate that mental health professionals' lack of communication especially about the diagnosis, treatment and care come as a result of the caregivers having limited or no knowledge on schizophrenia (Ferriter & Huband 2003, Milliken, 2001; Monyaloue et al., 2014; Shamsaie, 2015; Suryani, 2015). Similarly, Sibiya et al. (2019) comment that caregivers in their study pleaded with health workers to take a more proactive approach to involve them in the care plan of their ill relatives.

Some participants stressed how knowing about their relatives' illness may influence their perspectives.

Participant 1: "*I won't able to tell now, but maybe it will give me a satisfactory answer…I don't know how I feel. I have to wait until I hear…if I can at least find out what it is and if he will get better…that's all I want to know*".

Participant 6: "*I want doctors to explain to me in person where he got the illness or what happened. Because if you know, you understand and then you can accept the condition because you can't change it*".

From the above responses participants clearly want information to make sense of their relatives' illness. When participants lack information or clarity they will make sense of the illness according to their own experiences. Often times their experiences inform their understanding. The behaviour of the mental health workers shapes the participants' position of 'not really understanding schizophrenia'.

- ***Cultural and Traditional Beliefs***

In conceptualising schizophrenia, Participants 7 and 9 draw from their cultural experiences to explain the illness. The participants had the following to say:

Participant 7: "*What they usually say in our culture is that 'after a person gives birth they need to eat enough and stay warm'. Maybe my sister just didn't have enough food since she is not working. As a person who lived alone maybe she didn't have people who would cook for her. Also, maybe being exposed to cold might be the cause*".

Participant 9: "*It's witchcraft! Ehpraim was in Primary School for 11 years! I took him to social workers, and they said that 'he needs to be in special education* *schools'. But when I took him to Ministry of Education, they did some test and said Ephraim is normal and did not need special education. I prayed, and he got admitted at Eldorado High School for grade 8. He himself was desperate to complete school as he was scared that the government would say that he was too old for school. So, he was very determined to finish his school career.*

He was doing well, especially in accounting and entrepreneurship. But in April, my sister sent her employee to our home to give N$20 to my son. The day after he received the money he became so sick and didn't go to school. On another occasion, she gave him N$20 when she met him at the shop. The thing is that we didn't talk to each other during that time, so I was confused why she was giving him money. After these money transactions Ephraim told me that he would see his aunt's face in one of the teachers at the school. And whenever he would see this teacher, he would get angry.

*In May, she went to his school behind my back with her two brothers to go find out about my son's progress. That time Ephraim was busy in the exam venue writing exams. I don't know why she went there because we don't talk to each other, and my siblings don't support him. Now I'm sitting without a son, he was such a bright child… (*Burst out in tears crying uncontrollably*)…The teachers didn't give any information regarding Ephraim's school progress. He was asked where I was, and told that his aunt was at the school to inquire about him. He was very upset and called his aunt after school in my presence and swore at her. I went to the school*

> *the next day and told the teacher ‘that my sister may have come to the school to put witchcraft at the gate and that my family was not really interested in Ephraim’s progress at school’. He finished his exams and went to the farm for the holiday. The first week of school after the holiday he became mental”.*

The witchcraft narrative that Participant 9 mentioned is in line with the African and Asian literature provided in this current study. According to Iseselo et al. (2016), Tanzanian caregivers’ understanding of mental illnesses, including schizophrenia is that the illness is a curse or witchcraft caused by evil spirits; therefore caregivers consult traditional healers before they take their ill relatives for professional help. Similarly, caregivers in Nigeria and Taiwan would seek help from divine healers, and traditional healers when their relatives suffer from schizophrenia (Ae-Ngibise et al., 2015; Huang et al., 2008). Also, a study conducted in Namibia by Shifiona et al. (2019) on caregivers’ experiences, noted that some caregivers have consulted with traditional healers in a desperate attempt for their ill relatives to be healed. Therefore, a multi-disciplinary treatment model was advocated for South African caregivers – the cognisance to integrate traditional healing, and spirituality in the current biomedical, and psychotherapy approach (Monyaloue et al., 2014).

Not to negate the cultural and traditional influences of the participants in this present study; but the reason why schizophrenia was perhaps explained as witchcraft by Participant 9 could be because of the lack of knowledge participants have about the illness, since, none of the other participants in this study including Participant 9 have sought help from traditional healers or alternative sources for their relatives, except for medical intervention. Additionally, most participants reported that they do not believe in witchcraft therefore, did not explore that route even though some said that it exist. This current study's position is that schizophrenia is a mental illness. However, the accommodation of different perspectives is imperative in order to understand and meet the participants' needs, and simultaneously advocate for psycho-education and participant inclusion by mental health workers to enhance participants' knowledge on the subject matter.

4.2.1.4 *Abnormal Behaviour as an Indicator for Onset of Schizophrenia*

Schizophrenia entails positive and negative symptoms. The positive symptoms are more psychotic and involves seeing and hearing things which are not there, whereas negative symptoms are more overt behaviour such as diminished self-care, social withdrawal, etcetera (Barlow & Durand, 2012). Other prominent symptoms are disorganised features that can affect emotions, thinking and speech. Nonetheless, the onset of symptoms may presents itself differently in different people; hence, caregivers may not all be exposed to all the symptoms as they appear in schizophrenia.

Each participant in this present study narrated their experiences of the first episode as it unfolded. None of the participants in this study were previously exposed to any symptoms related to schizophrenia. Their first encounter with the symptoms occurred only in their role as caregivers for their relatives who were diagnosed with schizophrenia. They described the events/behaviour as abnormal. Abnormal behaviour is defined as behaviour, which is socially unacceptable in the study of psychopathology (Barlow & Durand, 2012). Participants clarify abnormal behaviour in their own words.

Participant 4: "*...normal people won't see babies in the fridges*".

Participant 7: "*You know, just certain things that a person does that you see is not normal*"

Participant 9: "*He is not normal like other people*".

- ***Caregivers Accused of Killing or Witchcraft***

Five participants in this current study observed that their relatives exhibited hallucinations and delusional symptoms. These are common symptoms among people with schizophrenia, and either one of them needs to be present for someone to be diagnosed with schizophrenia (Barlow & Durand, 2012). However, these hallucinations and delusions presented themselves differently for different patients. Participants 3, 6, 7 and 9 reported that their ill relatives' delusions were persecutory in its presentation. Participants were accused by their ill relatives of either wanting to kill or bewitching them.

Participant 3: "*Also he didn't sound good…he spoke weird things and his eyes looked wild. I then took him to Dr Schwindack. She told me that he was very sick and she explained to me about schizophrenia. The whole time he thought I wanted to kill him. He didn't want me to cook for him. He would read different types of newspapers and claim that there were people looking for him*".

Participant 6: "*He started hearing voices and seeing things. He would say that we want to kill him, that we are jealous of him, and use witchcraft on him. When he was in Primary School he became fearful, and was seeing things. Later on in his life he stopped eating and ran away from home. It was during this time that he lost his job in 2011. He was then seen by Dr Sieberhagen".*

Participant 7: *"She gave birth recently. Soon after giving birth she started to feel cold and warm. Her father's relatives took her to a clinic I think. She received tablets and went home. The next day she started saying things that was not making sense – she was talking about people who already died. That's when they admitted her and transferred her to Gobabis.*

She was talking about getting witched. The dead people took her kids and me and my other sister is witching her".

Participant 9: "*He used to say that we bewitched him. He was hearing voices and seeing things which we didn't. Some of the things he said were true but most of it wasn't. When I saw his behaviour I took him to the Social Workers and they referred me to the Mental Hospital*".

For Participant 4, the sister's positive symptoms were mostly hallucinations.

Participant 4: "*She went on about the babies in the fridge. Even if you asked her now she would tell you that she would see things…'I saw them, I used to see them, blood everywhere'*".

- ***Confusion***

Some participants reported on the thought and speech disturbances in their relatives' illness. The prominent symptom here was confusion. Participants reported that the ill relatives would jump from topic to topic or say nonsensical things.

Participant 4: "*My mum told me about it. When it first started she was in the north and I was in high school at the time. So I didn't know about her condition. They* *told me that she was confused when she started. She was just talking things that did not make sense. Then they realised that something was wrong, and took her to the hospital and that's when she was diagnosed*".

Participant 8: *"He was talking confusing stuff. The family members didn't also understand what was happening so they took him to the hospital and that is how they discovered that he had a mental issue. This was 30 years ago and Dr Kari and Hugo put him on treatment.*

He would jump from one topic to another. He goes off topic which is confusing".

Participant 9: "*He started saying confusing things*".

- ***Lack of Self-Care***

As with the positive symptoms, the negative symptoms are prominent in schizophrenia and serves as a criterion for diagnosis (Barlow & Durand, 2012). Usually, these symptoms would occur at the beginning of the illness as a warning of the onset of schizophrenia. When it appears later, the symptoms indicate deteriorating health of the patients. Participants in this current study, also witness negative symptoms in their ill relatives. The symptoms presented itself in lack of self-care. Participants 1, 6 and 8 were concerned about the hygiene of their ill relatives as they did not bathe.

Participant 1: "*The guy doesn't like to bathe at all!*"

Participant 2: "*If you asked him to bath he would ask 'where are we going?' But still won't bathe*".

Participant 3: "*When he came to me he didn't look good… his hair was long*".

Participant 7: "*She would walk barefoot and would not even bathe".*

Participant 9: "*He doesn't bathe and wears dirty clothes*"

- ***Extreme Strange Behaviours***

For some participants, schizophrenia occurred suddenly in their relatives without any warning, and the behaviour that accompanied the illness was very strange. According to Barlow and Durand (2012), these symptoms lean towards disorganised behaviour. Participants 1 and 5 had the following to say about how they experienced their ill relatives' sudden onset.

Participant 1: "*…he stripped himself naked and was running around naked so we took him to the Central Hospital and then they sent him to that side*".

Participant 5: *"He was normal. He was sleeping and when he woke up it was like that I saw it myself…it started while we were together. He said that his feet were warm, and then he got up and put a head scarf on. He then peed in a bucket and put his feet in. I was just lying and watching him. And then he washed his head with the urine because he said he was feeling hot. When I got up I didn't tell the children. I just got up and left because the children would have ran away. But I told my father to go to the house to keep an eye on him.*

When I knocked off and came home in the afternoon I took him to the hospital in the evening. I took him to Katutura Hospital. He was given an

> *injection, and we were told to come back in the morning. That's how we went to the Mental Health Unit at the Windhoek Central Hospital*".

The symptomology of the ill relatives as experienced by the participants, correlate with the experiences shared by caregivers in other studies. According to a Ghanaian study conducted by Ae-Ngibise et al. (2015), caregivers mentioned that they experienced sleepless nights, worry and embarrassment because of the unpredictable behaviour of their ill relatives. Although the above participants may not have expressed psychological distress with the sudden onset of the illness in their relatives, they are not exempted from emotional distress. Kamal's (2014) study asserts that symptomology of mental illnesses bear dire emotional triggers for caregivers through the different stages of the illness. As noted in the above analysis, schizophrenia symptoms vary from lack of self-care to erratic behavior, therefore, what may constitute as an emotional distressing behaviour for certain participants may not be the same for others. Nonetheless, the disturbing behaviour displayed by people with schizophrenia has the potential to elicit mental and psychological suffering for caregivers (Kamal, 2014).

4.2.1.5 *Treatment of the Illness*

People diagnosed with schizophrenia are treated with antipsychotic medication, such as Haloperidol, Risperidone or Clopixol (Patel et al., 2014). All the participants who were interviewed for this present study mentioned that their ill relatives were on treatment. The general consensus in this study, regarding the knowledge about medication, is the same as for the diagnosis and causality of the illness – lack of knowledge. Although participants were aware that their relatives were prescribed medication, they were uninformed about the purpose/function of the medication. Some participants had doubts about the effectiveness of the medication, while others were uncertain about the recovery of their loved ones. However, half of the participants seemed satisfied with the effectiveness of the medication, and the progress they witness in their ill relatives.

- ***Knowledge on Medication***

Most participants appeared to have some general information on medication, although they had various explanations.

Participant 3: "*I know it's an old version. And if a person is not on medication they become out of touch with reality*".

Participant 5: "*Yes, I know…he even knows it himself. He also goes to take his medication on time on the dates he has been prescribed*".

Participant 6: "*He collects his medication from the hospital himself. I think he now is addicted to his pills because he cannot sleep without it*".

Participant 7: "*They said she must eat enough because the treatment is too strong. The medication is very strong so if she doesn't eat she's going to start shivering or can even collapse because of the hunger*".

However, Participants 1, 4 and 7 gave the impression that they only knew that their relatives were on some medication but had no further insight about the medication.

Participant 1: "*It's just the tablets and the injections they give. Doctors just write the prescription and we get it at the pharmacy. We saw on the package how often he should take it*".

Participant 4: "*…all I know is that she should take medication that she gets from the hospital*".

Participant 7: "*They only gave the medication, and I read on the package how she must take it. You actually need to know what the tablets are for. Some tablets are for nerves…others are for something else. I just need to know what her tablets are for*".

- ***Function of the Medication***

In terms of the function of the medication, participants had their own interpretation of what the medication does. For many, the medication had a calming effect.

Participant 1: "*I think it's just to calm him".*

Participant 5: "*He doesn't jump around or make noise when he takes them. It's only the injection that makes him weak*".

Participant 8: "*Medication helps him to keep calm"*

Participant 3: "*It keeps him normal*".

From these observations it is clear that the medication meets its objective. Antipsychotics' main purpose is to manage and reduce the symptomology of schizophrenia (Patel et al., 2014). However, it would help if the participants were more informed in order to solidify their knowledge on schizophrenia.

- ***Effectiveness of Medication***

The following participants were satisfied with the effectiveness of the medication.

Participant 3: "*He responds very well on the medication that he is on now. He himself even said 'this medication works well', when I suggested that we maybe get him something that could motivate him. He refused as this works for him*".

Participant 5: "*The medication is good*".

Participant 6: "*Dr Marx prescribed him other medication, which he is currently on even at the state hospital. Those medication works better with him. At least he is able to function, and even has a part-time job compared to the previous medication that made him sleepy most of the time*".

Participant 8: "*The medication is the best treatment for him, the same way HIV people are on medication. We believe he must be on the tablets just like TB patients are*".

However, there were some participants who questioned the medication's effectiveness as they did not see change of behaviour in their relatives. As a result, some participants preferred alternative treatment methods.

Participant 5: "*These tablets that he is given…his behaviour is still problematic. I think he must always be given the injection. He becomes too strong if he doesn't get the injection. He needs to be injected so that he can stay at home because he doesn't stay at home. He runs around in town and places, and it's not nice for me. He is a big person, he is not a child*".

Participant 9: “*…maybe the treatment is not even helping…I think he needs stronger medication because the medication he is using now is not helping. His condition is not improving. I see his friend who is also taking medication looks better but Ephraim is not improving. He needs stronger medication because he doesn’t sit at home, he walks up and down, and I’ve been unable to sleep*”.

Participant 7: “*Is it proven that the medication is enough? That this person is going to be fine*? *Like us Herero’s we have medication for Diana’s illness; traditional medication that we use for that. It’s not herbs. You know the three-leg pot? We take the lid of the pot; we warm it up, and wrap it in a cold towel and put it on the head of the person. We do it in the morning, afternoon, and evening. This helps to keep the person warm because she was exposed to cold. But since she was aggressive we couldn’t hold or touch her. It was a bit difficult to treat her with that*”.

From these responses it is clear that participants want their ill relatives to do better. The injection has been proven to be more effective in some cases, especially when positive symptoms are more pervasive, and behaviour becomes uncontrollable, or if there is no improvement in the patient (Patel et al., 2014). However, this varies from case to case. To substantiate, Participant 3 has the following to say:

Participant 3: “*What happened was that they (health workers) didn’t give him his injection. He was not on it for about three months. One of the doctors decided that it was not necessary anymore. And I was wondering what was* *going on…because he is drinking medication but his health was going backwards? It's when I looked into his hospital card that I read that he didn't get the injection*".

This narrative confirms Patel et al.'s (2014) assertion that injections work better on positive symptoms, and as a result have better outcome on patients' illness management, which automatically reduces the burden experienced by caregivers.

- ***Non-Adherence to the Medication***

Some participants did not understand their ill relatives' refusal to take their medication. Non-adherence is a common challenge among patients with schizophrenia (Patel et al., 2014). Non-adherence is part of the pathology of schizophrenia. Participant 3 noted this in her consultation with a private psychiatrist when her brother was diagnosed with schizophrenia.

Participant 3: "*She did explain to me that they don't want to take medication and there's going to be conflict around that*".

The non-adherence to medication information was not readily available for all the participants. This is what some participants said about their experience with non-compliant ill relatives.

Participant 4: "*...She is refusing it. She's like 'ah ah I'm not taking this, I'm fine'. Like now she is in the hospital. When she comes back from the hospital she will take the medication maybe for a week. After that she will again start to* *throw it away when she feels she is fine or that God is with her and nothing will happen. I think she thinks she doesn't need these things*".

Participant 5: "*He doesn't drink the day time tablets. He only drinks the night time medication*".

Participant 6: "*He sometimes throws his medication away*".

Participant 7: *"There are days that this person doesn't want to take medication*".

Participant 8: "*It's a struggle to get him to drink the medication. Ephraim doesn't want to take his medication and refuses to go for follow-up. Sometimes he comes home only at 3 am when I am asleep, that means that he doesn't take his medication because I have to supervise him to make sure he takes them*".

These sentiments shared by the participants coincide with medication non-adherence challenges caregivers experience with their ill relatives in the South African context (Monyaloue et al., 2014). According to these scholars, the participants in their study, requested assistance from health workers to guide them specifically on how to deal with non-compliance and relapse situations. Important to note is that non-compliance to medication among schizophrenia patients can also be elicited by health workers' decisions to change patients' medication. This can create severe challenges for caregivers.

Participant 3: "*They didn't give him his injection. One of the young doctors there decided that it wasn't necessary anymore. What happens is when there is a slight change with his medication then he stops taking them. I think he forgets to take them. He thinks he drank them but then he doesn't. Then he gets really* *confused. Second day he skips his medication. Then he becomes a different person and every time it takes a long time to get him back where he was before*".

To alleviate this problem, health workers need to be adequately trained and knowledgeable in the subject matter as they are in the forefront, and have a professional obligation towards the public to convey correct information and knowledge. A South African study has found that health workers, specifically nurses, lack sufficient training on mental illnesses because they are unable to train or inform caregivers on schizophrenia, on how to manage or treat schizophrenia (Sibiya et al., 2019).

In addition, some participants felt that doctors do not listen to their advice on treatment.

Participant 3: "*You know I wanted to go there and attack them! I've told them on previous occasions that they shouldn't change anything*".

Participant 6: "*During the time he was seen by Dr Sieberhagen and he prescribed some medication which was very strong. Those medications made him weak and he slept most of the time. So when his work discharged him because he was unfit to work, we moved to the state hospital for treatment. However, the state health workers didn't review his medication and kept him on that same medication. The state doesn't listen to one's advice*".

The above experiences of the participants are supported by the literature. Caregivers in other contexts have mentioned the abrasive attitudes from health workers (Sibiya et al., 2019).

- ***Lifelong Illness***

Schizophrenia is one of the illnesses that are unfortunately incurable. Ongoing research is focused on managing symptoms to enable people to live operational lives, in addition to psychotherapy, antipsychotics and psychosocial support that exist (Ganguly et al., 2018).

Participants 3 and 6 were aware that the illness was incurable.

Participant 3: "*There is no cure. I don't think one can expect more, I don't think he will ever live a full normal life. Dr Schwindack said she wants to ask God one day why he made that illness; an illness that one cannot heal from".*

Participant 6: "*I heard at a PAN (Psychologist Association of Namibia) event when I asked questions on whether the illness has a cure.*

You have to tell me what this illness is about". *(*Referring to the researcher*)*

Some participants were aware that the medication was a lifelong treatment as indicated by the below statements.

Participant 3: "*It's lifelong. But with medication you can handle it. You can manage it with medication*".

Participant 7: "*It will be lifetime medication for now. I think she is going to be on the medication for life, but she needs to eat properly on time, and take her medication on time".*

Participant 8: "*It's not an illness where the person can stop medication. Maybe until they die. I haven't come across someone with a mental illness who came off the medication*".

At the same time, some participants were hopeful for a better outcome.

Participant 1: "*We don't want him calm! We want him cured! That's what I'm actually looking for*".

Participant 7: "*They say it's just a matter of eating enough and taking medication than she will be normal".*

However, Participant 4 had no idea about the curability of the illness:

Participant 4: "*No, all I know is that she should take the medication*".

4.2.2 Caregivers' Experiences in their Role as Carers

Many family members have become caregivers for their mentally ill relatives over the years as the deinstitutionalisation trend has increased significantly globally (Kamal, 2014; Marimbe-Dube, 2013; Monyaluoe et al., 2014; O'Brien, 2005; Oshodi et al., 2012). Caregivers, especially within developing countries, assume these roles because of the collective societies they are socialised in, and as result learn to take on the responsibility to care for their loved ones despite the burden associated with the role (Lippi, 2016; Shamsaei et al., 2015). Likewise, family members in Namibia have become caregivers for their relatives diagnosed with schizophrenia and other mental illnesses.

However, what was not explicitly communicated or known to the family members was the effect of the burden associated with the role. According to Cabral et al. (2016), several studies confirmed that people caring for those diagnosed with schizophrenia, specifically, are prone to experience extended social burden because of the debilitating nature of the illness. The burden is experienced both at subjective (psychological) and financial objective (financial and physical) levels. The former is concerned with the emotional and physiological health of the caregivers (Evans, 2009; Kamal, 2014), whereas the latter is concerned with the tangible aspects of caregiving, such as transport (Sibiya et al., 2019).

Participants' burden in this present study was predominantly felt in the objective context although the psychological impact was significant as well. This finding coincides with Nigerian caregivers' experiences of objective burden being dominant (Oshodi et al., 2012). The participants in this current study reported mainly on financial burdens and food insecurity associated with caregiving because most participants were from economically disadvantaged backgrounds. In addition, participants felt immense responsibility because they had to micro-manage their ill relatives because of their inability to care for themselves. The tasks involved, making sure those ill relatives took medication on time, and that their food was prepared. These responsibilities left some caregivers feeling deprived of personal time.

Participant 3: "*If my husband and I go out for dinner, I must make sure that there is food for him. If it was just me and my husband, I would have really lived off take-away!*"

Participant 7: "*I don't have time for myself! I'm forever just busy. If I'm not with the kid, then I have to go out to make plans to ensure there's milk* and *nappies for the child*".

Some participants had to play watchdog to safeguard their ill relatives.

Participant 1: "*He is someone that can just walk away from home. If he leaves in the morning he only comes back that time of the night. The life is as such that you can't leave someone like that unattended".*

Participant 2: "*So we must keep the doors locked from 7pm or latest 8pm because if he gets the gap then he leaves. You don't even know which direction he goes*".

Despite these challenges, all participants embraced their caregiving role and some even shared their positive experiences. The following themes substantiate the burden in detail as experienced by caregivers.

4.2.2.1 *Assuming the Caregiving Role*

Most participants in this study assumed this role because of their relationship with the ill relatives. Participants were predominantly either parents or siblings to the ill relatives; only Participant 4 was in a partnership relationship. As a result, many of them had very little choice to refuse the care role because no other person could carry their burden. This was especially evident among parent caregivers. Nonetheless, some participants felt that they were the best option for their ill relatives' well-being, hence they assumed the role. The common threat for all participants to occupy the caregiving role was because they genuinely cared for their ill relatives. This is what the participants had to say on assuming the role.

- ***Who will carry the Burden?***

Participant 1: "*There is no one that can look after him. He is just here at home so we take care of him. He is someone who can just walk away from home. And life is* *as such that you can't just leave someone like him* alone. *You need to watch him*".

Participant 4: "*It just happened maybe because I had a job here, and she was always struggling to get a job. As a result she didn't have enough income. Also, the person is your sister. You will just have to stay with her if you are the only person around who is very close to her. It's only me who is in Windhoek that she can stay with. There was a time she was staying with my uncle but they had misunderstandings. It is only I and she have this belief that she doesn't want to go to the north, so what else can you do?*"

Participant 5: "*Because I was the one who saw it when it started. There is no family! It's only his father who is alive but the father is in Omitara*".

Participant 6: "*Because he is my son. Who will carry this burden*? *I don't have a problem looking after him. Where is he going to go if I don't look after him! Who will look after him*?"

Participant 7: "*It's because I'm the only grown-up here. My mum is sick and I'm the only one who can help her out. My sister is small; she's still in school. She won't have enough time to study and take care of someone at the same time. That would be challenging for her schoolwork*".

Participant 9: "*It's my child. We live together*"

These responses indicate that participants had minimal choice in occupying the caregiving roles. Simultaneously, the responses also highlighted the lack of support caregivers have.

Additionally, Participants 3 and 8 felt compelled to take on the responsibility as they believed their loved ones will benefit from better care. This shows that despite having choices in life, our human need to care for one another precedes the burden that one is likely to feel in such roles.

Participant 3: “*You know personally I feel that my mum has no skills to work with children or to work with him, including her own children. I just thought let me take care of him. I just felt that I could do a better job even though I have little knowledge. Also, here with me he has my sons. He used to often go with them to watch cricket and drive around. He was more social then and it was good, if I think back now. So that is how it happened. He couldn’t stay with my mum; he would have died by now*.

And you know, my husband also worked for 10 years at psychiatry and I thought it would be great for my brother to live with us. He even said that it was good for my brother to stay with us. I definitely didn’t know what I was letting myself into!”

Participant 8: “*I am a curious person. If I come to your house and see some problems then I will approach you and maybe advise you on how to handle things differently. I took Michael because I found him at the Karibib prison. He raped a child and was there for more than a year. Whenever, I used to travel to Karibib I would visit him, but the family there didn’t visit him at all. Every time I went there he would say ‘I will die in the prison’. He was never charged. He was just in the holding cells.*

> *I saw his condition and I approach the ombudsman office, and that's how I got him out of there. There is a government rule that if a person is mentally ill the family can apply for release based on good behaviour. Since I was the one fighting for him we decided as family that I would look after Michael. But as we are speaking now, he said he wants to go stay on the farm. He needs to be in a surrounding where he can freely move. He needs space*".

- ***Self-Taught Caregiving***

Most participants in this present study had no prior formal or informal training or experience in caring for people diagnosed with schizophrenia. Many of them relied on the experiences obtained through living and caring for the ill relatives; what is known as on-the-job training in other contexts. According to National Academies of Sciences, Engineering and Medicine (2016), the majority of caregivers of older adult patients, who are suffering from chronic physiological and psychological illnesses in America, obtained their experience through trial and error that can bear grave consequences for the ill relatives and the caregivers. To support, Lippi (2016) asserts that caregivers of people diagnosed with schizophrenia are ill informed and do not have training on how to care for relatives with schizophrenia or manage schizophrenia, despite the burden associated with caregiving. Also, schizophrenia is known as a disorder that has high disability rate worldwide according to *WHO* (Cabral et al., 2016); meaning that these individuals depend highly on their caregivers for functioning. Participants had the following to say on having training in their role:

Participant 3: "*Mmm…not at all. I got my knowledge from practical experience. First, I used to fight with him about certain things; later on I learned and told myself that it wasn't his fault. He is very thin so I tried to help him to put on weight. He eats very little. He weighs 69 but he is about 3 meters tall (*scrolls through the phone and shows me a picture*). I don't know if you can see how skinny he is. He is tall but very thin. But then I also gave up on that because we fought a lot about what he should eat and how often he should eat. I realised that it wasn't worth it.*

I don't want to break him down; in the beginning I used to break him down with fighting and exchange of words because I used to think that he was stubborn and arrogant. But I must say that I have improved so much. I've learned with time".

Participant 4: "*Yeah I do…maybe it's not enough… (*giggles*) Just by staying with her because I have stayed with her for a long time now. You must just know what to say to her*".

Participant 5: "*I actually don't have but I stay with him. But I know how he behaves. I can see when he is not okay. When I see that things are getting out of hand, like arguments or loud noise then I lock the house and run to the Maxuilili Police Station to ask for help. The police would come and pick him up and drop him off at the hospital. Then he will be transferred to the Mental Health Unit, where he will get the injection and come back. Then it's good. We are able to sleep. We rest. The smoking of skunk stops for a while. And* *if he doesn’t sleep than he just sits around the house*”. (The participant seems comfortable and happy with this arrangement).

Participant 7: “*Mm*” (nods head approvingly). “*My mum is a psychiatric patient so we often took care of her and got the experience from that. But now it has been awhile since we had to take care of her. It’s now several years. It’s not the same but it’s close to that. Her symptoms are not like Mary who is walking barefoot. My mother’s illness is more like a heart problem. More like stress, something close to that”*. (The mother goes and takes her medical card and shows me. On the card her diagnosis is written as schizophrenia)

Also, some participants felt that even though they may not have initial training or experience in caring for people with schizophrenia that by simply being a parent provided them with sufficient knowledge to care for people with schizophrenia.

Participant 6: “*No, but since I was a young person I was trained by my mother to take care of my children, my house, and about neatness. I love him. When he was working he used to really look after me. God is there so there is no fear in taking care of my son*”.

Participant 8: “*Yes. If you have children, you handle people with mental health issues just like you would handle a child. All the kids are not the same so your approach must be also different for each child. That way the children will understand and respond differently, so approach is very important. We make him feel included in the decision-making in small tasks. Also, you cannot just keep him at home all the time. Involve him in everyday task,* *such as asking him to go with you on walks or running. Then he is happy. He likes running and playing with the kids. Treat him like a normal person*".

From these responses it appears that participants, despite their lack of experience in caregiving, are eager and are empathetic towards their ill relatives. A study conducted in the rural counties of Wisconsin, US, also found that caregivers felt growing sense of empathy towards their ill relatives in their role as carers (Chen & Greenberg 2004).

Out of the eight participants, Participant 8 was the only caregiver who had formal knowledge and experience because of her prior employment in the psychiatry wards.

Participant 9: "*Yes*. *I have worked in psychiatry wards from 2001 to 2002 so I know how to care for these people. I can handle it even though I'm not 100% confident in my caregiving role. Other people are worse off because they may not have experience*".

4.2.2.2 *Odd Behaviours Makes Caregiving Very Difficult*

Despite their willingness to care for the ill relatives, the participants were not shy to express their challenges and burdens associated with the caregiving role. All the participants said that caregiving was a difficult process since their relatives became ill. To substantiate the difficulty related to the onset of the illness, Riley-Mchugh et al. (2016) indicated that caregivers found the diagnosis stage to be particularly emotional. Also, Kamal (2014) suggests that symptomology (disturbing behaviours displayed by people with mental illnesses) can elicit mental and psychological suffering for caregivers.

Participants in this present study had the following to say on various challenges they encounter in their role as carers.

Participant 1: "*Sometimes one feels that it is hard. He is someone that can just walk away from home. And if he leaves in the morning he only comes back that time of the night. And the life is as such that you can't leave someone like that*".

Participant 2: "*So we must keep the doors locked from 7pm or latest 8pm because if he gets the gap then he leaves. You don't even know which direction he goes to. If you search for him then you have to argue.*

If we go to Rehoboth, then he comes along. But when he just wander off then you have to go search for him. So most of the time it's better just to stay here with him at home because if you go somewhere you have to constantly search for him. Maybe he gets frustrated by staying in one place".

Participant 1: "*Like now if he gets up from his nap and leave the house, then he'll go into any rubbish bin. He looks for cigarette butts then he comes home and makes a zol (*hand-rolled cigarette*) and smokes it in the house. If you tell him to go smoke outside, he just says he will do it now but then it happens again. Also he doesn't want to bathe. It cost, it is a fight to get him to bathe*".

Participant 2: "*If you tell him to bathe, then he asks you 'where am I going that I should bath'. And he will still not do it*".

Participant 3: “*Yeez! It’s a difficult situation! Sometimes it doesn’t feel* easy for me. *Sometimes I feel, ‘yeezy, does he have to stay in my house forever!’*

There is lot of things actually. At night he watches TV until late and then we have to stay awake as we have to put the alarm on. I also don’t want to tell him to switch off the TV too early but I don’t want to put a TV in his room then he will be in his room all the time. I want him to be among us and interact.

*Sometimes I sent him to go buy few groceries and he would buy the most expensive food. If I ask him, ‘now why did you buy the most expensive brand?’ then he would say ‘yes, one must eat quality’. Yaah...he spares no one’s money. Oh yeah, then I tell him you must fucking pay for that quality food (*says is with humour and laughs) *and then he tells me that he will. But again it’s also my money. I give him monthly allowance.*

Also, I cannot leave him at home alone thinking that he can look after my pets. Josephine who is my live-in maid needs to stay there because she has to look after him. It’s not like I can say he can look after my house. He is the one who needs to be taken care of. Everyone here in the office knows that I have to race home often because he is not eating or he locks himself in his room or I have to go the hospital. And these events happen at the most critical times when I have huge claims to submit for the business. In the middle of that, I must race home because something happened at home.

Then it’s Josephine, ‘Mrs Jacob, Jake doesn’t want to open the door, Mrs Jacob, Jake doesn’t want to do this’.

The first time he stayed with us my husband and I’s marriage almost dissolved. And that’s when I sent him to my mother and when he almost lost his life because of his health condition, that’s when I went and fetch him again. It was just too much! Even now, my husband and I fight a lot because of him. He doesn’t agree with what I’m doing and I feel that he is too strict with my brother. It’s difficult it’s not easy!”

Participant 4: “*Ogg it’s difficult…it’s very difficult! Just imagine someone that is staying with you, and for a whole week you don’t know where the person is. She doesn’t want to tell you. When you call her she answers nicely but if you ask her where she is, she will never tell you where she is. It is too hard! It’s too much…aahaahaah. It’s not for everyone! You wouldn’t even want to live with her because she is just too much! Sometimes she is coming home from church then that day she is fasting and we are not eating because she will not cook because of her fast. And she is one who is supposed to cook then no one will be cooking. Aah it’s just too much! (*Shakes head dismissively*).*

And sometimes you feel like she’s behaving like a small child. Even if the other sisters’ visit and you do something for them, then she feels like you love those sisters more than her”.

Participant 5: "*I feel like a dog…I don't know but it's getting bad for me. When I knock off and come home he waits like a big cow with his cursing. I don't think I will be able to care for him anymore. He makes me angry! Even when a child touches his personal belongings than a big argument erupts. For him there are only bad things. Even when you do well he always only sees the bad. Although I am the one looking after him, I am a dog. He sees me as a dog. He takes me as a dog. This whole neighbourhood knows about that. He breaks me down and swears at me. He even swears at his own daughter.*

Since he got ill I have a problem with quarrelling in this house. The quarrelling is the main problem. When I knock off and come home the man already waits for me. Just when I greet him he starts. His younger child and only daughter is apparently a problem. The other kids stay somewhere else. Even last night he was like,' this girl must move' so I ask him 'where she is supposed to go because she lives here'. It's very difficult!

He will even ask money from me and say 'when I get paid I will return it' but later when he gets paid it ends in an argument. The day that he is paid, the atmosphere is just tense, we just quarrel. He will talk about his money the whole night. I get tired…I don't know. We are together for 26 years and I get tired…for how long should carry this burden? I get tired.

You know when knock off from work and come home, you would expect the person that was at home the whole day to do something around the house. But no! When he wakes up in the morning and sits with his cup of coffee *that’s how I will find him when I get home. At least a person must clean the yard. Instead I would hire someone and pay them to come rake the yard or clean. He will not even fix the iron bar that has fallen off there*”. (Pointing in the direction the iron bar has fallen)

Participant 6: “*…everything gets difficult*”.

Participant 7: “*She is very hard to work with. Whenever you are helping her out you would think that this person is doing these things on purpose. She can even say ‘I’m doing this on purpose, I’m not sick’. And just spending your energy on someone who is saying ‘I’m doing this on purpose, I am not sick’… is the thing that makes me upset mostly. You get upset and get used to it. Mostly, I’m concern about the other people, the strangers that don’t know her condition. Even when a person is just passing by in the street, she would grab and hold on to someone’s handbag, and say ‘bring my handbag’, you know. And that person is perhaps late for work and my sister is just holding on to the handbag.*

Participant 8: “*These people are difficult to handle! Sometimes we ask him to wear closed shoes to protect his heels from cracking but he refuses. When it’s hot he would just walk around in a vest instead of putting a t-shirt with short sleeves and will also not wear his cap. But the thing is you cannot force him. He could even say he doesn’t want to be told nonsense! He wants a radio, a watch and we would buy it for him. But after a week he says we took his stuff. I’m not sure if he misplaced the stuff but after a while he will* *find it. He hides them away and maybe sometimes forgets where he hides it. They are difficult and could cost you your mind!*"

Participant 9: "*It's difficult to look after him. Ephraim also don't take his medication and refused to go for follow-up. He also doesn't sleep he walks up and down a lot at night!*"

- ***Loss of Freedom and Time***

Additionally, some participants in this current study felt that they had loss their freedom and have no time for themselves because they are engulfed with care duties. According to Leech and Dolamo (2016), caring for relatives with mental illnesses is time-consuming because caregivers' time is mostly spent on care responsibilities. These duties entail activities, such as cooking, cleaning and helping the relatives to take their medication (Oshodi et al., 2012), or bathing, feeding, and assisting ill relatives when nature calls (Ae-Ngibise et al., 2015). As a result of the demanding schedules, many caregivers are deprived from engaging in social life and relaxation activities (Kamal, 2014). These following statements are the experiences of caregivers in relation to their freedom:

Participant 3: "*The biggest challenge is the fact that I don't have freedom! In our room we have a hallway and my bathroom is also in there. But my brother will walk in there quite often whilst I'm sitting on the toilet pot. Maybe I should close the door but who closes the door in their own bedroom when you're sitting on the toilet pot? Sometimes I just say 'brother please just knock before you come in' but certain things are just don't register. Even if he is on his medication and I tell him to knock, he just carries on. But at least* *when he is on medication it goes slightly better, but he still just does as he is pleased.*

*He takes over our house. Currently, it's just basically me and my husband and then Josephine (*the maid*) that lives below. I cannot walk around as I wish in my house. I must always make sure I am dressed. If my husband and I go out for dinner, I must make sure that there is food for him. If it was just me and my husband, I would have really lived off take-away*".

Participant 4: "*ooh yah yah…sometimes the time is also an issue mmhh shiri shiri (*true true) *(*laughs*). Like you need your time but you just have to think about Elizabeth. I need my own time with friends, time away from everything. But then you have to think about Elizabeth…is she coming tonight or is she fine where she is? Sometimes you just trust that she is at home. Is she eating now? Because sometimes she fast too much…ah ah...You don't really have your own time".*

Participant 7: "*I don't have time for myself. I'm forever just busy. If I'm not with the kid, then I have to go to make sure there's milk and nappies for the child*".

Participant 9: "*I don't have time to look after myself as a woman like I used to! When last did I even buy clothes for myself? People give me clothes, even clothes that I don't like, but I wear them. What can I do?*"

4.2.2.3 *Emotional Distress and Physiological Health*

Additionally, participants in this current study said they have experienced emotional distress since the onset of the illness. A study conducted by Caqueo-Urízar et al. (2017) suggest that schizophrenia caregivers' mental and physical health is gravely compromised compared to non-caregivers or those caring for people with Alzheimer's disease or epilepsy. Furthermore, mothers of children diagnosed with schizophrenia in a Canadian study viewed the illness through a lens of family and confirmed that the illness is definitely a family illness because it affects everyone (Milliken, 2001). The emotions felt by the participants in this present study were mostly worry and fear, which were triggered by the behaviour of the ill relatives.

- ***Worry***

Most of the participants' emotional distress in this present study has been associated with the caregivers' inability to control the wandering of the ill relative. Wandering away from home is a common behaviour among certain psychiatric illness including schizophrenia, which bears severe burden for caregivers (Ahmad et al., 2006). Participants in this study were worried when they did not know the whereabouts of their ill relatives but also felt angry. According to Hirsch and Mathews (2012, p. 1), worry is defined as a primary cognitive characteristic of anxiety – a chain of thoughts and images that negatively affect us and are relatively uncontrollable; and is concerned with future events that are uncertain but contains the possibility of one or more negative outcomes. Participants had the following to say:

Participant 1: "*Sometimes one gets worried if you haven't seen him for the whole day*".

Participant 2: “*You search for him but you don’t even know which direction to begin. He has his own routes that he walks. You have to search for him constantly*”.

Participant 4: “*She likes walking away. Sometimes when you have misunderstandings with her she would just decide that she will go. She goes to the houses of people whom she goes to church with. You will even notice that she stays away for a whole week without coming home and if you ask her the person will just say ‘I’m in Windhoek’ but she will not tell you where she is. She doesn’t want you to know her whereabouts.*

Windhoek is dangerous but the person keeps on leaving home without informing anyone. Who knows where the person is? She will get you worried most of the times…you’d be thinking where is she now? When you call her she will answer, but she will answer the phone without revealing her whereabouts. That’s why sometimes you just have to let her be wherever she is.

There is a man in her church, so she sometimes just stays there. But now I have at least his number. At least when she’s not home, I can call him. I also have numbers of other people in her church in case she doesn’t come home maybe to ask when she will be coming”.

Participant 7: “*You just go where she is and beg her to come home. Sometimes she makes as if she is sleeping and we think everything is fine and we also sleep. When we are asleep she dodges (*runs away*). Even at midnight. We only receive calls from people who know us or her father. The people will usually call* *the father and he will call to inform us. Then we will go there and beg her to come. There is a bus station for Omitara buses close to the single quarters; that's where she goes mostly. When my mother goes and gets her she would come home. With my mother she doesn't have a problem, she will always come back. But when my sister and I go we just need to hold her until our mother comes and get her*".

Participant 8: "*Here in Windhoek we are always worried if he goes somewhere alone. Even if he maybe goes for a walk or to the shop even if it's not too far from the house. We worry if he is safe because of the cars. One day he got angry and walked away. He said he had a headache and got into a taxi but the taxi driver noted in his behaviour that he was not okay so he dropped him off at the police station. But at the farm he will feel free. He needs to be in a surrounding where he can freely move around, he needs space*".

These responses clearly indicate that in addition to the emotional turmoil associated with the wandering of the ill relatives, the participants have to play watchdog to protect their ill relatives from getting harmed or cause harm to others. According to Ahmad et al. (2006), wandering patients may be at risk of physical, psychological or sexual abuse. More specifically, Pejlert (2001) mentions the importance of locking doors to keep the persons with schizophrenia safe. Participants in this Windhoek study reiterate these safety measures.

Participant 9 said that her worry also contributes to lack of sleep.

Participant 9: “*He walks away from home in the morning and sometimes only comes home at 3 am. So I can’t lock the doors because of that. I can’t rest! We don’t sleep in this house! I don’t sleep well. My sleep is a big problem! I worry a lot*”.

Coinciding with this finding, many caregivers of people with schizophrenia in other contexts raised similar concerns of sleep deprivation. According to Kamal (2014), the unusual sleeping patterns of people with schizophrenia involves often being awake at night and sleeping during the day, which causes substantial burden for the caregivers. A Canadian study that focused on mothers' experiences with children with schizophrenia found that the mothers were predisposed to sleep-related disorders among other disorders (Milliken, 2001). Caregivers in a Ghanaian study expressed that they were unable to sleep because of the ill relatives disturbing behaviours, such as walking up and down at night, or talking non-stop (Ae-Ngibise et al., 2015).

Participant 6 mentioned that her worry was mostly associated with the verbal abuse she experiences from her son, especially when he defaults on his medication and substitutes that with alcohol.

Participants 6: “*There are times I get worried because when he drinks he gets verbally abusive towards me and daughter and say that we mistreat him*”.

The above concern raised by Participant 6 resonates with caregivers’ experiences in other studies. A study conducted by Brain et al. (2018) with caregivers of treatment resistant schizophrenia individuals, mentioned that these caregivers were worried about being harmed by their ill relatives. To substantiate, Ferriter and Huband (2003), noted that caregivers in their study were worried and fearful that their ill relatives might physically harm them and those around them. These concerns expressed by the participants in this present study and caregivers in other contexts are warranted. As a researcher, I have experienced this same worry, but mostly fear for my safety and the participant's, because the partner of the participant whom I was interviewing for this present study, became verbally abusive when he found out about the study upon his return home. His behaviour was bordering on physical abuse because of the aggression that was involved in his expression and body language.

Some participants were worried about the extent to which they had to micro-manage their ill relatives. Participants 3 and 8 felt that they have to constantly keep an eye on their ill relatives with every task they carry out because of their inability to do things without supervision. The participants had the following to say:

Participant 3: "*Especially, the constant worry because I have to monitor him like a baby. I'm always thinking what is going to happen next with the medication? I phone almost every day to see if he has taken his medication. It also puts pressure on my maid but yeah what can I do. It is what it is*".

Participant 8: "*You have to monitor him whenever he engages in a task. For example, if he waters the plants, he will fill the water up to the brim of the plant pot and the water runs over, or if he cooks porridge he would pour in too much maize meal unless you tell him to stop*".

- ***Fear***

In addition to worry, some participants in this current study mentioned that they felt unsafe and fearful for their lives because of the destructive behaviours of the ill relatives. In support, Ferriter and Huband (2003) state that behavioural problems such as verbal aggression and violence were frequently described as causing shame, emotional distress and instilling fear in caregivers. Suryani (2015) asserts that fear for safety was usually associated with caregivers when there is history of destructive or violent episodes. Steimer (2002) explains that we feel fear when our lives are threatened or when we perceive a threat, which can be psychological or physical, and we either respond by fleeing, fighting or freezing.

Participant 5: "*The problem I have with him is the fact that he doesn't drink his daytime medication. He only drinks the evening ones. I fear for my death! He smokes during the day that's why he doesn't want to drink the medication! He smokes skunk! I heard that skunk is very dangerous. It's very dangerous to live with this person! We don't have rest! When does one even sleep? He can even stab you to death in your sleep! My family can't even visit then it is a big problem. He has a knife which is sharp on both ends…he wanted to stab my sister with that knife. How do you stay with such a person? It's a very big problem! I don't get rest…he is chatting now as if everything is fine…but he will start soon* (says it with humour*). We won't get rest. He should go stand at the Mental Health Unit for Christmas so that we at home can have some rest and be happy for at least during Christmas time!*"

Participant 8: "*If your approach is not proper he can beat you so you need to be calm. If not, you can aggravate him. You must be able to control yourself and not get angry when he is behaving badly. These people can tell when you approach them with a bad attitude, so I approach him with love.*

He gets easily angered. When he gets like that you just have to leave him to calm down. There are times that he wants to beat us but we just ignore him. Sometimes he would say things like 'the blood will flow today'. The reason why he is currently admitted here (Mental Health Unit) is because he became very aggressive with the children because they were playing in the yard after he cleaned it, so he threatened to beat children with a rake".

- ***Anger***

Furthermore, Participants 4 and 7 felt that their relatives were deliberate in their actions, which warranted their anger or frustration.

Participant 4: "*You get frustrated sometimes because of the way she behaves. She is talking to you nice but she will not give you the answer where she is. That angers me. Sometimes you feel like she doesn't care what other people feel or think! She doesn't care whether you're angry, she just does her things*".

Participant 7: "*When you beg her to do something she will just tell you that she doesn't want to do it. Although you want to help the person, sometimes her attitude and behaviour angers me mostly because she just doesn't want to do what you ask her to do*".

The responses above show that Participant 1 specifically felt frustrated, whereas Participant 7 was mostly angry. Anger has no definitive definition as there are various components involved, such as physical, psychological and social. Also, it encompasses various emotions that range from frustration to rage and is experienced by all humans at some point in our lives (Shahsavarani & Noohi, 2014). However, the anger felt by the participants in this present study was goal-directed behaviour. Meaning, the frustration and anger resulted because the participants were not able to control the behaviour of their ill relatives – or the circumstances in the outside world prevented them to have their desired goal, which was the expectation for their ill relatives to comply with their requests, whether it was to eat or take their medication on time (Williams, 2017). When this compliance was not received from the ill relatives, the caregivers felt frustrated and angry; making their anger or frustration goal-directed behaviour. Important to note is that most participants did not have sufficient knowledge of schizophrenia and how the illness influences the behaviour of their relatives. Therefore, it makes sense for them to become frustrated or angered by their ill relatives' behaviour.

- ***Depression/Sadness***

Some participants experienced feelings of depression. Depression is a mental illness that affects a person's thoughts, feelings and behaviour, and is usually characterised by low mood, sadness, helplessness and hopelessness (APA, 2013). The participants said the following about their psychological health:

Participant 1: "*Some days you feel sad*".

Participant 3: "*Ag, sometimes when I look at him and I see that he is not going out, but we are going out, and he stays at home and just sits there, yes, it takes a toll on me. Emotionally, I feel sad and sorry for him, but then I also think to myself it's the best that he can get*".

Participant 6: "*This illness also makes me very depressed. Sometimes I feel I should gas all of us so that we can die because how long are we going to suffer*.

It's sad to see a young person in that condition, you will not understand until you are in the same shoes".

Participant 9: "*Sometimes I get angry but I try to deal with it. I cry a lot when I'm especially alone and think of my son and his illness*".

From the above responses, the evidence indicates that these participants were emotionally affected by what was happening to their ill relatives and the toll caregiving had on their mental health. Participant 6 explicitly noted feeling depressed, while other participants mentioned sadness, one of the key symptoms in depression diagnoses. These feelings experienced by the participants resonate with caregivers in other studies. According to Riley- Mchugh et al. (2016), as much as 90% of caregivers experience moderate to a severe burden; with those caring for individuals diagnosed with schizophrenia specifically at higher risk of developing mental disorders, such as depression and anxiety, compared to those caring for dementia patients.

- ***High Blood Pressure***

In addition to the psychological distress experienced, some participants in this present study commented on their physiological health. Physiological illnesses, such as hypertension, heart attacks, and sporadic chest constrictions, on top of psychiatric illnesses, were experienced by mothers in Canada who cared for their adult children with schizophrenia, (Milliken, 2001). Participants in the current study had the following to say:

Participant 5: "*My dear I have a heart condition and my high blood pressure is also very high now! Luckily, I don't have cancer otherwise I would be dead by now! I don't look forward coming back to this house. In the mornings when I leave home I feel good because I'm happy at work but I drag coming home because I know this person is waiting for me like a big lion when I come back home. I get discouraged when I know that I have to come back to this house again*".

Participant 6: "*My brain is also getting tired. My blood pressure was also very high, but thank God, I haven't had a heart attack yet!*"

4.2.2.4 *Financial Burden Associated with Caregiving*

Most participants in this present study said that the financial burden was their primary concern, followed by food insecurity in their caregiving role. In concurrence, caregivers in other contexts also found financial burden distressing (Kamal, 2014; Lowyck et al., 2004; Milliken, 2001). Another study noted that schizophrenia carries a huge economic cost on the government and society at large (Maiocco et al., 2017). The annual global cost estimated for treatment and other expenses vary between \$32 and \$65 billion (Maiocco et al., 2017).

The lack of finances not only affects the quality of life of the participants but in turn the patients' well-being. In congruence of the negative impact lack of finances have on caregiving, Cabral et al. (2016) mention that the presence of poverty deteriorates the health of the patients and consequently, increase the burden on the caregivers. When caregivers are financially compromised it jeopardises their caregiving as opposed to when they are financially stable. Participants shared the following on their financial responsibility and challenges.

- ***"I do Everything"***

Seven out of the eight participants in this current study were either employed in low paying jobs or were unemployed, but interestingly were also the breadwinners in their household; providing food, transport cost and other unforeseen expenses.

Participant 4: "*I stand for everything; food, transport, accommodation. Yeah these are challenges but you won't just sit and worry about it. Money is sometimes an issue but it's just how life is. It's just life. You won't have everything in life.*

She used to work. But the problem is after some time there's always a misunderstanding between her and the boss. Also, when she was working she didn't want to share her money with anyone because she was saving her money for a church trip".

Participant 5: "*I do everything…we have a gas bottle so I will fill up the gas.*

When he was working there was at least some income even though he was drinking alcohol that time. But now you don't even see his pension salary. He says he has debts but you don't see what he is taking on credit. The salary he gets finishes on skunk! He doesn't buy food. The only thing he *buys is soap. The other day he bought only maize meal. When you ask him for money he says 'I'm paying off debts', what debts does he have? I don't even see a child that he is supporting and he has three children. We don't know where his money goes!*

*We only hear that he has gone to get his pay. I'm the one who pays for his taxi when he goes to get his pay and also when he goes to the hospital for his medication. Sometimes I'll give him money from my work taxi fare and I'll instead travel to work on credit using the bakkies that you pay month end. When I don't have money, then his daughter would zula (*struggle*) taxi money for him. But when he comes back after he gets his pay he only buys zols (*joint*). You don't even see a penny! Apparently he paid his debt…what debt does he have! You must at least see what the person has taken on debt".*

Participant 6: *When he worked he helped me and his sister financially. I'm the only breadwinner now and the financial strain is worrisome".*

Participant 7: "*Finances obviously is a challenge. The first thing is the children (sister's children) who are at a boarding school in the village. I need to travel there, to take them some cosmetics and food. You have to look after the children's well-being. The children usually call after two weeks saying 'we are hungry or we need this for the school'. Like when they get homework, they do not have the means to buy what they are required by school. They have no means, there's no close family there so that is the challenge.*

*On the other side, there is this is this one (*Pointing to the baby lying on a blanket in the living room*). I have to take care of this one, every day I have to bathe and feed him. It's a nice routine to have since the child came to stay with us, but the child is on formula milk and needs diapers too. The big tin of milk last only for two week. He takes it only for two weeks then its finished! So per month you need to buy like three or so big tins. And the granny doesn't work, I don't work and these things need to be bought*".

Participant 8: "*Michael eats four times a day. He eats at 8 am, then 1 pm, 4 pm and then 8 pm. But most of the times he watches TV till late so he will also need a snack before bed time. And because he is on medication he gets bigger portions compared to the rest of the family. We are nine people in this house. Every month end we have to make sure to buy him chicken whether it is KFC or Hungry Lion because it's his payday, or sometimes he needs to be on a special diet so all of that cost money. Even though he gets his grant it doesn't mean that we can use it only on his food. We have to sometimes put fuel in the car when we take him to the hospital whenever he needs to collect his medication or when we come to visit him. Or we add N$200 towards water and electricity bill. Everything cost money these days*".

Participant 9: "*I cannot even afford electricity for my room or buy food. Maybe next month the cash loan that I took out will be paid off, and then I can pay electricity. For now they have disconnected all the cables in my room. It's a family house so there are also a lot of arguments. My current job will*

> *finish soon as well then I'll have no income. This bed is only planks, there is no mattress* (shows me the bed).
>
> *I buy him clothes even with my last pennies. The other day I bought him a t-shirt with my last N$100. The poverty is too much*".

The above shared narratives are similar to what many caregivers experience in their role. According to Opuko-Boateng et al. (2017), Ghana treats about 32% schizophrenia cases and family members are the primary caregivers. However, most of the caregivers are either unemployed or pheasant workers and earn meagre salaries, yet have to cover most of the non-medical expenses related to schizophrenia, such as transport and other household expenses (Ae-Ngibise et al., 2015). One can only imagine the burden experienced by the caregivers.

To alleviate the burden felt by caregivers, caregivers of people with schizophrenia in Belgium brought the attention of cost involved in caregiving to the government and mental health fraternity (Lowyck et al., 2004). In addition, the participants in this present study felt that the financial burden was intensified because of their ill relatives' unemployed status. In response, Kamal (2014) asserts that the symptomology of the ill relatives makes it challenging for them to be employed but also highlights that people with schizophrenia lack social and life skills that further fuels their unemployment status, which subsequently increase the burden felt by the caregivers.

Only Participant 3 expressed that financial burden was not currently overwhelming for her.

Participant 3: "*Agg…it's through grace that we are this old and we can provide. When he was staying with us in the past it was an additional mouth to feed so it was more difficult. But now it's better in that regard. Obviously I could have used that money towards my children so that they can set-up businesses but it's also fine for me. The finances are not much of a challenge.*

- ***Unforeseen Financial Cost Caused by Ill Relatives' Behaviour***

Some participants said that they incurred additional expenses that were unforeseen because of the behaviour of the ill relatives. Participants 5 and 9 shared the following:

Participant 5: "*I have struggled a lot. If I buy something and bring it home, then he will throw it out or hit it until it breaks…dishes or anything. It will get thrown out of the house. He breaks pots as well…those are the things this man does! That pot cost money…the three-legged pot. He broke it and threw it on the ground. I can't really do anything in this house.*

Once he even sold this plot that we are staying on. He then spent the money on alcohol. It was during his illness, 2012 or 2013. I went and got the police, and the police asked in all our presence whether I have also agreed to sell the plot.' I said no, not when it's so difficult to get accommodation'. I had to pay back the money to the buyer".

Participant 9: "*Financially I cannot cope because Ephraim threatened someone and he was locked up. So I had to find a lawyer to bail him out. That is how I ended up at the cash loan*".

These concerns raised by the participants coincide with caregivers experiences in other studies. According to Kamal (2014), schizophrenia patients' behaviour can be destructive and can result in damaging of property. In addition, Milliken's study (2001) mentions that parents usually incur further cost, such as bailing out their children when they find themselves in trouble with authorities or pay for flight costs when they disappear from homes.

- ***Future Financial Woes***

Some participants in this current study were also concerned about the future of their finances because they were approaching their retirement age.

Participant 3: "*But I also want to say that I have children and one of them stopped working. Next year I am turning 60 and am supposed to retire but I will not retire because I have responsibilities. But I won't say that I will not retire just because of the responsibilities, but I'm also thinking what will I do? Just sitting at home? But I definitely have to work longer than I was supposed to*".

Participant 6: "*I desire to have my own house because my boss who is helping me with the rent is getting old and had an operation recently so I cannot always depend on her. I'm hoping that my daughter gets a job before I turn 60 years so that she can look after him when I retire. I'm getting old and the body is also failing me physically*".

These above concerns come as no surprise because most of the participants in this present study, as mentioned earlier, are primary breadwinners, despite having other responsibilities other than caring for their ill relatives. Currently it appears as if the Namibian government is not doing enough to lessen the burden of the caregivers. The government's lack of assistance towards caregivers of people with mental illnesses, more so schizophrenia, is also a concern in other countries. According to Shamsaei et al. (2015), caregivers in Iran requested financial assistance from the state to help reduce their burden as they are unable to care for their loved ones due to financial constraints. Additionally, a study in India proposed that the government spend the required budget suggested by WHO on mental health issues, in order to minimise the expenditure family caregivers carry due to caregiving. Furthermore, Iseselo et al. (2016) note that caregivers in Tanzania often have to pay for antipsychotic medication for their ill relatives when the state does not have medication or the prescribed medication. Namibian caregivers are not exempted from the cost related to medication, because the country also experienced a shortage of psychotropic drugs as revealed in *The Namibian* newspaper (Kangootui, 2018).

4.2.2.5 *Lessons Learned*

Despite the challenging tasks of caregiving, some participants expressed that the caregiving process is rewarding as they are learning from their experiences. According to Chen and Greenberg (2004), caregivers in their study reported positive gains in their role as caregivers. The scholars suggested that 70% of caregivers reported being more empathetic towards people with disabilities, while 50% were able to prioritise time to important matters in life such as family (Chen & Greenberg, 2004). However, the gains experienced by participants in this present study varied from person to person.

Participant 3: “*I certainly do things differently compared to if he wasn’t around. It’s the same as with my dogs; I don’t want to be away for long from home then I start to feel that I neglect them or him. So yeah my life is based around him. A lot of times ‘I feel jeezy! I can’t go out again for the night as Jake is alone’. Not that he is bothered but I feel responsible like I am with a child just like I’m responsible for my animals. Yeah so definitely I have become more homebound.*

You know maybe because I’m also older it doesn’t bother me a lot. But sometimes I think ‘yoh! Is this really how my life has to be? Is it really how I must feel?’ My children are out of the house and now must I really look after someone else? Yeah, sometimes it makes me feel a bit frustrated but most of the time I think also its better that he is here, he could have been dead. I actually went to bid him farewell but then I brought him back. It’s grace. I couldn’t have handled it emotionally if both he and my dad’s lives were short lived”.

Participant 4: “*I’m more responsible now. I would say you get more mature. I can handle difficult situations now, not like other guys. You know guys my age; I don’t think some of them if you give them a person like my sister would be able to cope with stressful situation like hers*”.

Participant 6: “*It taught me how to accept my son no matter the condition. You have to look after them. Some people are left by their relatives at the hospitals without a care. I have become resilient and a stronger person. Before, I* *used to cry a lot about our living condition but it was with his illness that I got closer to God*".

Participant 7: "*Sometimes she makes you laugh (*smiles*) even though you are angry. You just see yourself laughing. It has made me more accepting, because I have done this before for my mum and I got used to that*".

Participant 8: "*It gave me new experience and love. I learned more about human behaviour. Even though I was a supervisor before, taking care of Michael helped me to improve in how to handle and interact with people. It's like I'm in a special school, it increases my love. Michael put me in a school*".

From these accounts, one can deduce that most participants in this current study have positive experiences, which coincide with the narratives shared by caregivers in Chen and Greenberg (2004) study, referenced above. However, not all experiences were positive. Participant 5 had the following to say:

Participant 5: "*Even if I look after him I a dog. He sees me as a dog. He takes me as a dog*".

From this response it seems as though Participant 5 felt mistreated and unappreciated by her partner. There might be an element of resentment or disappointment in the manner the partner responds to her despite the caregiver's efforts. According to Iseselo at al. (2016), the continuous problematic behaviour of the ill relatives and the financial hardship involved in the caregiving process can make caregivers feel helpless or even elicit negative feelings.

4.2.3 Caregivers Coping Methods and Support

Numerous studies have postulated that the people that suffer mostly in caring for those diagnosed with schizophrenia are family members that occupy the role of a carer (Kamal, 2014; Rafiyah et al., 2011). Coping methods are fundamental in the maintenance of the caregivers' well-being as their stress levels inadvertently affect the caring of the ill relatives. Caregivers globally apply different techniques to cope with the illness and its impact (Kamal, 2014). Likewise participants in this present study used different coping techniques despite having very limited coping mechanisms and support systems. Participants expressed experiencing psychological and practical burden as indicated under theme 4.3.2.3. In order to cope with the subjective burden, techniques such as prayer and attitude modification were considered helpful. Most of the participants did not have much choice but to cope with the burden.

4.2.3.1 *Coping with Subjective Burden*

- ***"God is a Doctor of All Doctors"***

Believing in God, prayer and attending church is one of the common coping mechanisms used by caregivers globally (Kamal, 2014, Iseselo et al., 2016; Pejlert, 2001). Some caregivers believed that conceptualising the illness from God's perspective, made coping easier (Rafiyah et al., 2011), while others believed that prayer gave them hope (Iseselo et al., 2016) and strengthened them (Sibiya et al., 2019). Similarly, most of the participants in this present study believe in God and found prayer or attending church helpful in coping.

Participant 1: "*Sometimes we take him to church and we also go to church*".

Participant 5: "*We pray…every Sunday we pray. There was even a whole church in this yard. But he didn't listen to the church. While we were praying he would swear at us*".

Participant 6: "*Only prayer is the medication of all things*".

Participant 7: "*I go to church. Mostly, when you go to church you meet different people and talking about your challenges to other people is also a relief. You can't talk to the same people all the time, it becomes a routine*".

Participant 8: "*Sometimes we go to church for prayers. You can see there is a change in his behaviour once you've been to church with him. 'God is a doctor of all doctors'* ".

Participant 9: "*I read the bible a lot. Or I would call my friend's to pray with me when I used to have a phone. He also gets prayer from the pastors but he doesn't sit through a service in a church*".

- ***Compassion, Acceptance, Love and Gratitude***

Another coping mechanism that the participants in this current study applied was to understand that their ill relatives' actions were not deliberate. This understanding made them compassionate towards the ill persons, which fostered acceptance for some participants. According to Chen and Greenberg (2004), about 70% of caregivers in their study reported that they have become more empathetic towards people with mental illnesses, and also experienced increase in patience and understanding. In addition, Pejlert (2001) mentioned that parents in a Swedish study found that the acceptance of the illness, being hopeful for a better prognosis for their children and focusing on what is going well in their lives helped them to cope better.

Participant 1: "*What can you do? He didn't do this to himself. So you just have to accept him*".

Participant 2: "*Sometimes I just feel sorry for him because of how he is. He wasn't that type of person before".*

Participant 3: "*I mean he has got the illness. It doesn't help that I cry over that the whole time. I can't change the illness. It is there to stay with him so that's how I tell myself. But I feel sorry for him especially when you see everyone is going out and people are doing things. He hangs out often with my children but that's it. Other than that, he has no one to go to or goes anywhere*".

Participant 4: "*I think for me it's like I get angry fast and then forgive fast also. Maybe she is doing this because she is not fine*".

Participant 7: "*I would like to say to other people who are facing these challenges they must always support these people. Family is the most important support system they have. So all we need to do is to accept that person*".

Participant 8: "*…I just accept that there are people with that illness. I have accepted that I cannot heal him and he has to live with people just like other people do. I must just treat him in a good manner*".

Additionally, some participants felt that loving or showing love to the person is helpful for them.

Participant 6: “*Love is important above all*”.

Participant 7: “*…Give the person love and the person will be normal. The person is just a normal person*”.

Participant 8: “*I approach him with love*”.

Participant 9: “*…He himself knows that I love him*”.

Participant 7 found that gratefulness was an effective coping tool for her.

Participant 3: “*I must say since my father’s death, and this is about 30 years ago, I feel stronger. I feel I can cope and I feel good.*

Gratitude…I mean if I look at people it is very difficult for people. I never slept hungry. I always have money. I’m working since I was 13 years so I always had money. I have a roof over my head. I have children who are full of love, they carry me on their hands, and I have good health. So I am very grateful. If there is a moment that I dwindle off, I tell myself ‘Sara straighten yourself’. I don’t allow myself to go there. And I have a grandchild”. (Smiles broadly and shows me the picture)

- ***Accommodating the Behaviour of the Ill Relatives***

Some participants have come to understand that they cannot change the behaviour of their ill relatives. As mentioned in Kamal’s study (2014), the disruptive behaviour which is often displayed by people with schizophrenia is part of the illness. To cope with the disruptive, aggressive behaviour or what some participants in this current study described as stubbornness, participants have developed adaptive techniques, such as changing the style of interaction to either keep the peace or to make living easier with the ill relatives. Adjusting one’s approach or choosing words carefully have been identified as significant coping tools in keeping peace (Kamal, 2014).

Participant 4: “…*You must know what to say to her. Just go along with what she says even it’s not the truth or the reality. You don’t have to stop her from attending church; you must just let her do her things. However, there was a time we disagreed about going to church because she was asking for money to go Nigeria and expected the family to pay for her ticket and we said no. That time she got angry and got herself a job to pay for her trip”.*

Participant 8: “*Most of the time you have to agree with him otherwise he gets angry. Even if you know that what he says is not the truth you have to support his statement. That way, you avoid conflict, and he would be happy. You can’t say no to him. If he does things which are unacceptable then you need to approach him in a nice way and tell him that what he did was not good, but in the same breath to say something positive, such as let’s go for ice-cream or offer him tea. That way he just focused on the positive things and not the negatives. Sometimes he threatens us for example; he would say things like ‘the blood will flow today’. So you have to find a good way to encourage him and to help him forget about the negatives.*

Don’t chat back or explain things, he doesn’t want explanations”.

Participant 7 has realised that to get her sister to engage in certain tasks, such as bathing she needs to use manipulative tactics.

Participant 7: "*Whenever, you want her to bathe you need to convince her that she needs to bath because she can't go to church without bathing. So I would say 'I have prepared water for you so that we can go to the church'. Since she's a person who likes going to church she will bathe*".

- ***"Get Over It"***

However, some participants felt that there was nothing more they could do, but just get over their emotions.

Participant 1: "*I feel sad, but I don't think about it…so that it can pass by*".

Participant 7: "*You will get angry but if the person says 'I'm not going to do it', what are you going to do? Just get angry and get over it*".

Additionally, Participant 4 said that having a hobby helps him to cope.

Participant 4: "*Sometimes when I go to my friends and watch soccer it helps. When I watch soccer all my problems go away. You just enjoy the game*".

Engaging in hobbies as a coping mechanism has been found to be helpful among caregivers of schizophrenia (Kamal, 2014).

4.2.3.2 *Coping with Objective Burden*

Objective burden is the greatest burden experienced by participants in this present study because of their socioeconomic status. In addition, participants rarely have any support to alleviate the hardship experienced in their role as caregivers. Lack of money and food are the main challenges most of the participants find difficult to cope with. Nonetheless, most of them mention that they manage with their limited resources and have crafted sustainable methods to endure the hardship of lack of resources intensified by caregiving.

- ***“I Manage”***

Participant 1: “*We help each other here at home to search for him, to lock doors and give him food*”.

Participant 4: “*I stand for everything…my parents are old now. Both are pensioners. Sometimes you just don’t give her money…I just don’t give her at all*”.

Participant 5: “*I manage. I make sure that I buy a lot of groceries month end. It’s usually just the meat...but if there is donkey meat for sale then I take it on credit for N$900 and then I pay it off month end*”.

Participant 6: “*In terms of food, it’s not a big issue, we eat what we have. He is also getting his pension grant so that helps towards food and transport for his son’s school.*

Participant 7: “*We eat what is available. My mother is a pensioner and she’s getting the pension money. And she also has two ghettos (*shacks*) that she’s renting out but the money is not enough because she needs to pay the house, my sister’s school fees and buy bread for the kids every day. But we are trying. We really are*”.

Participant 8: “*We just cope. People at our house don’t stay without food. Michael gets his pension money plus we are renting rooms from which we get income. We just cope. We have eight children some which are our biological and* *others that are family kids. Michael is the ninth child so we just treat him like we are treating our children with their differences*".

Participant 9: "*Sometimes I use my taxi fare on food or I take food on credit at the Cuca shops (offline shops). Or sometimes I go to people's houses* and ask for *help. According to Christianity I'm not supposed to be a beggar but the situation I'm in I don't have a choice*".

These responses above indicate that participants have built resilience in the role as caregivers. Resilience, according to Richardson (as cited by Zausniewski et al., 2010, p. 2), is defined as the process of coping with adversity, change, or opportunity in a manner that results in the identification, strengthening and enrichment of protective factors. Chen and Greenberg (2004) posit that caregivers in their study have developed increased resilience in their caregiving roles. In support, Zausniewskie et al. (2010) noted that resilience among caregivers of mentally ill people have been correlated with reduced burden among family caregivers, better psychological well-being, improved quality of life and enhanced knowledge and understanding towards the ill relatives.

When participants were asked whether they receive any help regarding their objective burden, some participants mentioned that they receive some help with money or food.

Participant 3: "*My mother pays a small amount monthly. But she's not much help. I don't actually don't want to talk about her because it's another story. She gives something. Basically for the past 5 years she gave me N$1200 for each year. But this year she started off with N$2000 so at least it's something. I buy his clothes from that, it helps a bit*".

Participant 7: “*Sometimes the father* (Diana’s father) *brings money, which is also not enough, but it helps because by the time he brings the money we are already broke. Sometimes my other family members bring a pack of nappies or something*”.

Participant 9: “*Church lady helps me. She would give me cooked food*”.

Participant 6 was receiving help towards her rent.

Participant 6: “*My boss helps me with my rent. I prefer to live in a peaceful environment because that helps me to cope. The space that we are renting is very comfortable compared to the previous place. And my son is flourishing and is at ease. God has been a blessing in my life, he makes away*”.

Living in a peaceful environment is very important for Participant 6 because she understands the significance the environment has on her son’s well-being.

4.2.3.3 *Lack of Social Support*

According to Cabral et al. (2016), schizophrenia, specifically, is associated with long term social burden and has a high prevalence rate worldwide. Although, African families are historically collective, it appears that when mental illness is present, families become more nuclear (Iseselo, 2016). This has been attributed to the stigma attached to mental illness but also the lack of education of the general population on schizophrenia. Nevertheless, social support is an integral part in the coping of the caregivers. Studies have indicated that when caregivers receive support the burden is lighter and they cope better emotionally and physically, which in turn has a positive impact on the ill relatives (Rafiyah et al., 2011).

- ***No One to Talk to***

Participant 1: "*No, I struggle with him and so we carry on*". "*Occasionally, family members would ask me how he is doing*".

Participant 4: "*I don't talk to anyone about the problems. Yeah my family, my sisters call me a lot of times and ask how Elizabeth is doing. And my mother is always calling asking 'is she fine? Is she doing great? Is she eating?' They all ask these things. It is only when they call and ask that we discuss about Elizabeth. If no one asks…I just don't tell. Even my friends, I don't tell them about my sister's illness. I don't*".

Participant 5: "*No one. Who must I talk to my dear? I knock off late. I'm only off during weekends, the rest of the week I work*".

Participant 6: "*Family is not very supportive; instead we are jealous of each other".*

Participant 7: "*No. Like I said my sister passed away two weeks ago and now my brother. So mostly, these people are in critical situations and they also need some support".*

Participant 9: "*Since this thing started, it's only me for the past year and four months. I am alone. I don't have family. I was rejected by my family including my mother. I sometimes worry what will happen to him when I die. But most* *of the time kids in the neighbourhood are supportive. If they see him taking his clothes off they come to tell me*".

The above responses indicate that most of the participants lack social support from families and communities. This implies that these participants are isolated and, therefore, the burden felt could be intense.

Compared with other participants, Participant 3 is the only one who mentioned having a support system.

Participant 3: "*I must say my husband; even though we fight a lot and have differences, supports me. My children are extremely supportive, including their partners. I have an extremely praiseworthy family. They mean everything to me*".

Studies indicate that when caregivers receive family support they are better able to cope in their role as caregivers (Rafiyah et al., 2011). Additionally, caregivers experience good quality of life when they are married and are informed on the subject matter (Opuko-Boateng et al., 2017). These findings resonate with what Participant 2 shared.

Although stigma was subtle in this present study, Participants 1 and 8 shared their accounts of the stigma experienced in their community, which inadvertently heightened the social isolation. According Iseselo et al. (2016), stigma has been identified as the driving force for isolation among caregivers.

Participant 1: "*He helped the kids in the street a lot, now they don't acknowledge him anymore. Now that they are above him, they don't worry about him* *anymore. They just keep them to themselves. That's what doesn't make me feel good. They don't even give him a cigarette but he was the one who was helping them. The community members instead treat him like a dog now, and he was the one helping the children in this street with their schoolwork. When he walks in the street they treat him like a dog. They don't have to treat him like that. They can at least just treat him good. It's not because he did something to himself that he is like this; something that has happened to him. It could happen to them one day as well, and then? They themselves know that he helped their children throughout, because of him their children are employed now*".

Participant 9: "*When I walk in the street people will point fingers to me and say 'that's the lady with the crazy child'. People also said that it's my own witchcraft coming back to haunt me. Some children also mock him and reject him*".

- ***No Formal Support Groups***

Most of the participants noted that they did not know of other support groups that exist nor did they receive emotional support from such groups if it exists. Participants had the following to say:

Participant 1: "*No support. It's just when we ask that church people come around. They don't come here out of their own*".

Participant 3: "*No. I don't know of any support groups. Dr Schwindack even said she doesn't know of a support group*".

Participant 5: "*No*".

Participant 6: “*No. But I also heard that Miss Namibia assist people with mental illnesses but I just don’t know how to get hold of her*”.

Participant 7: “*No, it’s just us*’’.

Participant 9: “*I was at the Red Cross but they said they only work with prisoners. It’s just the church people who help me. He gets prayer from the pastors. The pastor also said that his main problem is alcohol and marijuana. If he stops that he’ll be okay”*.

These responses clearly indicate that caregivers have been actively seeking for support but that the lack of formal support in the mental health community deprives them from getting the help they need. According to Purba (2017), caregivers can benefit from support groups, because they will learn from people with similar experiences through sharing but also gain hope and strength.

- ***Lack of Awareness of Counselling Services***

There seems to be a lack of awareness or interest in seeking counselling. When asked if they have sought counselling support, participants said the following:

Participant 3: “*I went once this year for therapy but it was about my relationship with my mother. I had counselling when my dad committed suicide. That was crucial. But now I’m good.*

Participant 4: “*No, maybe it just didn’t come to mind*.

Participant 5: “*No, what is counselling*?”

Participant 7: "*No, I have never. I thought of it but time is just not on my side, maybe in the future. I think they offer it at the hospital*".

Participant 9: "*A counselling service that involves family members would help*".

The lack of awareness or lack of interest among participants regarding therapy could be attributed the invisibility of the counselling services offered by the state. Hence, most of the participants in this current study did not attempt to seek counselling as a support system. Agreeing with the existing lack of formal support available for caregivers of schizophrenia relatives, a Ghanaian study urged their government and respective stakeholders to provide broad social support systems for affected caregivers in the form of counselling, public awareness on mental illnesses (Ae-Ngibise et al., 2015).

4.2.3.4 *Interventions Requested from the Government*

As indicated earlier, the burden experienced by most participants in this study was predominantly tangible. Participants were concerned about putting food on the table for their ill relatives and lack of finances.

- ***Basic Needs***

Participant 1: "*The only thing that I would like to apply for is the food they give. But I don't know where to apply. The Harambee food will really help*".

Participant 5: "*We used to get Harambee but it got stopped because he gets pensioners money*. *If I have to receive help it should be at least food assistance*".

Participant 7: "*I went to this Life Changing Centre and they said they only give spaghetti and packets of soup. They don't give formula milk anymore. So any help is welcome. Either with nappies, formula milk, clothes for the children*".

Participant 8: "*Food help is also welcome because Michael eats like a child so there needs to be food at home always. There's a difference between how much people eat who are on medication and those who aren't*".

Participant 9: "*I would also like food*".

Additionally, Participants 4 and 6 highlighted the need for financial assistance.

Participant 4: "*Maybe financial*".

Participant 6: "*Financial help is welcome. I work at two different places. I have a full-time job from Monday to Friday and weekends I work at a guest house. I do lot of ironing work so it really takes a toll on my body. It's tough physically but I have to because of the situation that we are in*".

The need for financial help has also been identified by caregivers in Iran. Caregivers in that context requested financial assistance from the government to enable them to give better care to their love ones (Shamsaei et al., 2015). However, the above narratives on food insecurity and money shed light on the socioeconomic inequality gap that exists between the rich and the poor people in our country, affecting more so, the caregivers of individuals with mental illnesses. According to The *World Bank Document* (2017), although Namibia is a young country and sparsely populated, and has minimised the poverty gap significantly since 1993, the country is still considered to have a high poverty rate internationally, compared to countries that share the same income per person. In 2015, 16.9% of the population lived on less than $1.90 a day (The World Bank Document, 2017), which is equivalent to N$28.82. This statistic gives an indication of what most participants in this current are experiencing, a position not shared by the 20% of the population who are economically better off.

Additionally, the narratives support the assumption that the mental health aspect is not prioritised in terms of budget allocation in the country because of the needs highlighted by the caregivers for the ill relatives. According to Suryani (2015), each country is supposed to allocate 3% of their health budget to mental health services; however, this is not the case in India as only 9 billion rupiahs of the 21 trillion rupiahs of the health budget is distributed to mental health.

One could argue that although Namibia is one of the very few countries in the world that offers a disability grant for people with mental illnesses, the country still fails to prioritise the significance of mental health. As a result, the budget allocation for mental health could be compromised. According to Dhaka et al. (2017), the country is under resourced in terms of mental health workers and mental health hospitals for a country that treats 8000 Namibians according to *News24*. Also, the lack of antipsychotic medication as highlighted in *The Namibian* newspaper (Kangootui, 2018) speaks to the insignificance placed on mental health in the country.

Other needs that the participants highlighted were specific to their experiences in the care role. For example, Participant 9 felt that having a television set could keep her son out of streets whereas; Participant 6 believes that having a house will be beneficial to her son's well-being.

Participant 6: "*My biggest need is a home. When we were evicted from our former place I involved social workers. So currently, we are fighting with the municipality for his plot which he applied for in 2007. We are still waiting on the feedback from the municipality".*

Participant 9: "*I would also like a TV and a bed. If the TV is working maybe he will stay at home. He walks up and down. If he doesn't walk up and down he will not get alcohol or marijuana on the streets. I don't want him to get grant money. I have refused. Just because he has a mental illness doesn't mean that he should be on grant. Life has no limits so we shouldn't limit ourselves. Also, I think when he gets this money people will follow him around and he has to buy marijuana for them*".

- ***Community-Based Mental Health Centres***

The need for community-based mental health centres beside the Mental Health Unit at the Windhoek Central Hospital has also been highlighted in the present study. A centre that will not only be patient friendly, and nurturing to the well-being of the ill relatives, but will also offer a variety of services to both the ill relatives and caregivers, was desired by many participants in the study. Participants expressed that having such a centre could be helpful to them especially when the ill relatives are experiencing psychosis, or are unmanageable as they have reservations about the current state of the Mental Health Unit.

Similarly, a Nigerian study by Taiwo et al. (2008) proposed for human-centred facilities or less restrictive mental institutions like “rehabilitation villages” as a pathway to absorb mentally unstable individuals; of which the majority of them are diagnosed with schizophrenia and were dumped by their caregivers at the long-stay hospitals.

Participant 3: “*You know when he was off the trolley I contacted Schwindack and asked who she can recommend…and Dr Schwindack recommended Belinda Bruwer. Except that, I was looking around for places and that’s how I came about this leaflet of Bel-Espirit…yeah there are no places really.*

*There is a time that they are not on their medication. When he was not on his medication my mum put him in Stukland for three months. But when he was off his medication and he was with me yoh! (*Exasperation expression*) he was difficult! And such times it would be good if he can be with doctors in a place where he is taken care of. I would rather contribute if there is a place like a centre where he can be looked after.*

I’m not someone who has a lot of time but this is a very important issue for me. So I wish that there will be facilities. Even if I maybe work less…then I will really do outreach for spiritual healing because I see that my family is bloody crazy (laughs). *I want to see what I can do*”.

Participant 4: “*If they could come up with a place, but not for them stay there. I don’t think they would want to stay in that place. It’s also not good to make them stay together. i When you do that it might look like you’re discriminating against them. It’s just fine when they stay with their families I think.*

I would rather prefer maybe centres for these people where they can get information and go with their caregivers and together maybe get counselling occasionally".

Participant 7: "*Also maybe a centre can help because she doesn't want to stay here. She is just staying here because she doesn't have any other means or way. But staying there would be beneficial for her. She would be taking her tablets on time and eating on time. And then maybe you can take the children there to visit until she gets well*".

Participant 8: "*Maybe it would be nice to arrange activities for them like sport days where they can all participate- football tournaments. He likes to play football*".

Additionally, one of the participants from the pilot study reported the following:

"*There are also other families with similar problems and can set up community centres where people can come and volunteer. Like now, these people are locked up, these are intelligent people! Locking them up is like locking up their minds! These people have experiences that can be used. The centre can interview them and utilised them in the areas that they have expertise in. The centre can also organise sports days and patients can participate. For me it will mean freedom for these patients. Students who are unemployed especially, those in nursing and related fields can be employed at these centres*."

On the contrary, Participant 8 felt that she would like her son to get some social skills.

Participant 9: “*I want him to get training at Kayek and work for himself. Just because he has a mental illness doesn’t mean that he should be on a grant. Life has no limits so we shouldn’t limit ourselves.*

According to Purba (2017), social skills enhancement programs can include aspects, such as career training and occupational psychotherapy. Furthermore, the scholar posits that schizophrenia patients who received rehabilitative intercessions had improved social skills compared to those who did not receive the intervention.

4.2.4 Caregivers’ Experiences of Service Providers

4.2.4.1 *Difficulty Accessing Medication*

Some participants in the present study expressed that they had difficulty securing medication for their ill relatives. This causes havoc at homes for some participants because they are unable to manage the ill relatives without medication. Sometimes the ill relatives’ behaviour is perceived to be life threatening to the participants. Participants had the following to say about the accessibility of medication.

Participant 3: “*They don’t have always! If I ask them why he didn’t get medication then they would tell me the tablets were finished. That’s the most heart-breaking thing. My brother stays with us in the flat…but with others maybe they beat them up or they lock themselves in. They must do something! There was a day that I threw stones at him because he wasn’t on his medication and was walking away from home and didn’t want to come home even when I was telling him to. It’s a good thing thinking back now, that the stones just missed him. Imagine, I could have hurt him in the process, and I’m not an* *aggressive person. But I feel for those poor people who don't have the same insight as I have now, how their lives are interrupted…it is heart-breaking*".

Participant 5: "*No…they don't have medication all the time. Like now he doesn't have evening medication. Sometimes he gets different tablets also. One time he had yellow and another time he had blue. We struggle…even at the clinic there is none! He finds it difficult to sleep. He says that 'his head is attacked by bombs when he is not on medication'. We really have difficulty with pills. The fact that he doesn't sleep at night because of the shortage of tablets contributes to extensive quarrelling. Actually if the medication is not given on time it becomes a problem for someone who is crazy to be without medication. That causes quarrelling. We don't sleep… he will kill you! These people must get their medication on time, just like us high blood pressure suffering people. There was a time that the clinic didn't have high blood pressure medication, and I was admitted four times already in this month*".

Participant 7: "*…Mostly, they don't have it for my mother. Like now she needed medication and it was out of stock. My brother wanted to get it on his medical aid but couldn't get the prescription in his name. They then gave her something else instead.*

However, for my sister they always have medication".

The issue of lack of medication is not a novelty in the Namibian context, but is also not exclusive to Namibia only. Similar experiences are shared by Tanzanian caregivers, as shortage of antipsychotic medication propelled caregivers to fend for medication for their ill relatives, incurring additional expenses in the process (Iseselo et al., 2016).

However, some participants reported that they receive medication on time.

Participant 7: "*Yes, they always have medication for my sister…but*".

Participant 8: "*Yes, he always gets his medication*".

Participant 9: "*He always gets his medication. There wasn't a day that he didn't get his medication. Maybe we are just lucky. I was wondering if we can't pay a small fee like N$4 if you have, to help the government because these drugs are expensive*".

4.2.4.2 *Caregivers' Needs from Health Workers*

- ***Psycho-Education***

Most participants in this current study felt that they lack information and knowledge about schizophrenia that could help ease the burden associated with caregiving. Participants requested detailed psycho-education intervention on the cause, diagnosis and treatment plan of schizophrenia. Studies assert that when caregivers are better informed of schizophrenia, their quality of life improves, and inadvertently the well-being of the ill relatives (Kamal, 2014); meaning that ill relatives can have better prognoses (Evans, 2009). Participants shared this sentiment.

Participant 3: "*They must give a whole list of things that you need to know…how you must manage the person. I don't want to break him down. In the beginning I used to break him down by fighting with and exchange of words because I used to think that he was stubborn and arrogant*".

Participant 4: "…*Maybe also to educate one on how to handle the situation when she relapse, and to teach me skills on how to interact with her. All of these things are necessary*".

Participant 5: "*They must tell me anything about the illness*".

Participant 7: "*I would like to really to know what else is needed in terms of this sickness*".

Participant 9: "*I would like training on how to care for the person, what type of food they should eat. That way, I can even do community work and assist other people who have same challenges as Ephraim*".

Some participants expressed the need for psycho-education on the cause of the illness.

Participant 1: "*I just want to know what is happening with him…I don't know where I will get that answer from, from whom? What happened…?*"

Participant 4: "…*Explain to me what the causes are and what exactly this illness is*…"

Participant 6: "*…Where he got the illness or what happened? Because if you know, you understand and then you can accept the condition because you can't change it*".

Participant 8: “…*And what the cause is of the illness*”.

Other participants needed health workers’ intervention in the medication aspects.

Participant 3: “…*And the medication as well. If my husband didn’t tell me that they don’t drink their tablets, that they keep it in their mouths or throw it away then I wouldn’t have also know*”.

Participant 4: “…*If there’s a solution when the person doesn’t want to take their medication*”.

Participant 5: “*These tablets that he is given…the behaviour is still problematic*”.

Participant 7: “*There are days that this person doesn’t want to take medication…she doesn’t eat at all. In those situations what am I supposed to do? How do convince her to eat and take her medication?*”

Additionally some participants wanted to know more about the diagnoses.

Participant 4: “*The name…*”

Participant 8: “*I will like information on the diagnosis*”.

- ***One-on-One Communication***

Furthermore, most participants in this current study felt that health workers rarely include them in anything relating to their ill relatives’ illness. As a result, they felt the need for personal contact with the health workers on a one-on-one basis, especially on the psycho-education of schizophrenia. Participants were of the opinion that one-one-one conversations with health workers will grant them the opportunity to ask additional questions that may have, but could also help them to gain better understanding of the illness in order to support their relatives better. Face-to-face communication has been found to be the most effective way of communication because it makes room for clarity and transparency.

Participant 4: "*I would like them to sit with me*".

Participant 5: "*I want to be called in and told in person*".

Participant 6: "*I want doctors to explain to me in person*".

Participant 7: "*I can even sit with the doctor and make notes while he is talking*".

Participant 9: "*To explain things to me face-to- face, first with me alone, and then with my son*".

Important to note from these responses is the need for family psycho-education. Family-focused psycho-education is considered to be helpful as it empowers family caregivers to become more helpful in improving the ill persons' capabilities but also in accepting their behaviours (Suryani, 2015).

Additionally, some participants stressed the need for written content so that they can share with other family members. Leaflets are considered to be effective in the dissemination of information because participants can always revisit a written document anytime they need to refresh their memory on the subject matter. Participants 7and 8 said the following on how they would prefer the information to be cascaded.

Participant 7: "*I think noting down or getting a leaflet to explain to other people will be helpful*".

Participant 8: "*Something to read, a leaflet*".

- ***Inclusive Language Use***

Additionally, some participants felt that they were not adequate in the English language, therefore, may not understand the information communicated to them by the health workers. Participants requested that information be communicated in their local languages.

Participant 6: "*Language is a challenge most of the time. There are no Damara/Nama speaking people and one doesn't clearly understand what the doctors tell you because not all of us can speak English. Some of us grew up in the Afrikaans era*".

Participant 7: "*Maybe she will be going back to Omitara and those people who live with her everyday also need information. They need to be educated about this. The people who live with her are Hereros so information provided in Otjiherero will be good*".

Participant 8: "*The thing is I also only understand English 20% and when I read I jump some words which I don't understand. Otjihero would be better so that other people who will take care of him can also understand. One can easily read and explain in Otjiherero to other people*."

According to Squires and Faan (2018), language barriers in America in the health settings have an impact on the service delivery between nurses and patients as the country has diverse ethnicities due to migration. To provide satisfactory service and to ensure that language barriers are bridged, medical translators are suggested in health sectors or priority be given to employing staff from different ethnic groups. This will ensure that medication instructions are given in a preferred language of the patients which could prevent or minimise non-compliance, which often results from misunderstandings (Squires & Faan, 2018). The Namibian context can apply these helpful strategies in order to provide an effective and competent service to participants and their ill relatives.

4.2.4.3 *Experiences and Perspective of Psychiatry Wards*

Historically, psychiatry wards are considered to be inhumane for people with mental illnesses. Hence, the initial motivation behind the deinstitutionalisation movement was to restore the dignity of mentally ill people but also to give them freedom (Kamal, 2014).

- ***Not Good***

Most caregivers were against the idea of having their ill relatives hospitalised at the Mental Health Unit. Participants felt that the psychiatry ward's environment was not human friendly and conducive for the well-being of their relatives. Some felt that the environment worsened their relatives' condition but since they were not adequately trained and informed of how to handle their ill relatives they regarded the hospitalisation helpful at times. Participants said the following:

Participant 3: "*I feel that place is not good. I would rather contribute if there is a place like a centre where he can be looked after. I can't put him in that place (psychiatry). I don't know if you agree…I don't know if you were there?*"

Participant 4: "*Aah…that hospital is not nice…I just feel like when you visit there and even see other people that are being visited, they are little bit fine but the place…they don't want to be in there. They just want to get out. I wouldn't want anyone to stay in that hospital*".

Participant 6: "*The hospital setting is not good for him. He needs his space, clean and neat environment*".

Some participants felt that the wards were not demarcated according to the progress of the patients. This finding is supported by Shifiona et al. (2019), who noted that limited resources, such as a lack of staff members and wards in state facilities perpetuate the illnesses of the patients.

Participant 7: "*These people are not getting services. These people are just kept together in the same ward. Even if the person is not that worse they are kept with someone who is worse. This one is beating the other; the other one is doing something else. They should have separate wards based on the people progress. For example, a ward for people who are worse, another ward for people who are little bit better, and for those who are doing better. Instead they are all put together in one ward. People who are worse are placed with the ones who are better and the ones who in-between. I think that is also a challenge for those who are inside there*".

Participant 8: "*People at different levels are put together in the ward. Also, he doesn't like being admitted here because the people at different levels are put together in same wards. The ones that are worse and those that are slightly* *better or better are all place in one ward. Even the other day when we brought him her, he was asking 'why the other patients were so dirty or naked'".*

Pilot study: "*Psychiatry is not a prison! People can be grouped according to their progress*".

Additionally, some participants expressed that their relatives' self-care and well-being have deteriorated since they have been admitted.

Participant 4: "*When she is discharge I would rather have her in the north where my parents are and my older siblings. At least she will be taken care of. When she was there (north) she was even fine. But now she looks so thin. When I ask her she said she was fasting for a week during her admission*".

Participant 8: "*When he is here sometimes his self-care lacks. His things such as his clothes and shoes get lost. Maybe the other patients take his stuff. Like now, he came in with clean clothes but when I come back another day he'll be barefoot as he is likely to lose his sandals*".

Some participants felt that they were rejecting their loved ones for taking them to the Mental Health Unit for admission. Hence, participants in this present study were adamant about having their relatives at home with them instead of having them hospitalised. Participants were of the opinion that their ill relatives need to be in a nurturing environment with their families. Several studies have indicated that psychosocial support has a positive impact on the well-being and prognoses of schizophrenia patients (Evans, 2009; Kamal, 2014).

Participant 4: "*I'd rather have her at home, not in the hospital. At least at the house she converses just like a normal person. But in the hospital …ah I wouldn't want anyone there. At least you can give her tasks to do to keep her busy. She can even cook. Nah I'd rather have her at home not in the hospital*".

Participant 6: "*Putting your person in the hospital is like throwing away your person. People need love. When he is admitted I'm the only one who goes to visit him. At least when he is here with me at home, there is freedom and he can visit his friends*".

Participant 8: "*Michael is not better in hospital. He needs to be around people. To be free so that we can also learn how to handle him*".

Participant 9: "*For him to stay with me so that he can get the love of his mother. They also give love because I used to work there but the love of the mother is good*".

On the contrary, some participants felt that hospitalisation was good for their mentally ill relatives for various reasons. Participant 6 felt that hospitalisation ensured that her sister's needs were taken care of, such as having meals on time, which alleviated her worries.

Participant 7: "*Being in the hospital is better since she is eating properly that side. It's not that there's no food here. She just doesn't want to eat this food here because we are witching her. So at the hospital she's eating properly and bathing on time and doing everything on time. Here if you give her soap you want to witch her, even if you give her clothes it's a problem, blankets it's a problem. We are witching her*".

Additionally, Participants 3 and 5 felt that hospitalisation of their ill relatives would provide them with a much needed break and relief from the burden associated with caregiving.

Participant 3: "*I would tell you now but I'm not going to repeat this again… (*Seems ashamed for mentioning this*) I would prefer if he was in the hospital but I won't tell anyone. Because I have my own life… you know. I work full-time and I have a lot of responsibilities and then I have him as well. But I feel guilty for saying this. Most people have someone they look after or care for. So yeah I guess this is mine*".

Participant 5: "*I feel he must go stay in the hospital and only come out when I feel like because he is getting worse now. He uses drugs and everything mixes…his tablets are not supposed to be mixed. His medications are strong tablets but since he stopped drinking alcohol he uses drugs. That skunk…it's the strongest. He must go stand for a while and when I feel like it then I can go get him.*

It's October now…I think when he goes to get his medication they should admit him. He must go from November to December. I will go take him for few days over the festive season for Christmas, and then he can go back again. That will be good so that we can also stay happy. You don't know how you will eat Christmas or do your things…it's not nice. One gets tired. He must go stand for a while. If he drinks his medication as instructed we won't have these problems".

These responses indicate that caregiving indeed is an exhausting task. Hence, an Indian study suggested that caregivers be provided with paid re-spite care, which will relieve them from care duties occasionally, with the aim to release the burden associated with caregiving (Suryani, 2015). Although, this care method might not be available in Namibia yet, perhaps the Mental Health Unit serves this purpose indirectly for some caregivers despite its limitations in terms of bed capacity.

4.2.4.4 *Overall Service Experience*

- ***Inconsistent Doctors***

Most participants in this current study expressed their frustration with doctors who are frequently changed at the hospital. As a result, the participants lack consistent information about the progress of their relatives.

Participant 1: "…*Every time you get another doctor*".

Participant 3: **"***Unfortunately what happens at the state hospital is that…there was a fantastic doctor. I can't remember his name. He was from elsewhere Nigeria or Tanzania but I can't remember his name. He was a great man…ugh! They are there for six months and then they are gone again. Then comes the next person and it seems that the next person wants to change the medication again…one can't really fiddle with the medication that much. It's very bad.*

That is why I so want him to be on our medical aid so that we can get him to people that I can speak to".

Participant 6: "*The only problem I have is that doctors aren't consistent with the patients. There is always a different doctor every time so you never get to hear the real story*".

Participant 9: "*…It was a Cuban doctor but I think that he has left now*".

Additionally, some participants were disheartened by the manner in which the health professionals treat their ill relatives. Health workers' harsh treatment of patients has been identified as a determining factor that prevents patients from seeking help in South Africa (Sibiya et al., 2019).

Participant 3: "*I don't know if it's part of your interview, but they handle state patients really bad. And these people aren't able to look after themselves. Not even my clever brother that was an advocate for a long time can care for himself*".

Participant 6: "*The nurses are unfriendly. Nurses back then had love for the patients but now there is no love*".

Participant 9: "*We used to really care for the patients, it wasn't about the money. But these days it's different. We were very caring and loving*".

Some participants highlighted the incompetency of the health workers in various situations. In support, several studies have pointed out the incompetency of health workers, particularly nurses, in relation to the treatment and dissemination of information (Milliken, 2001; Pejlert, 2001; Sibiya et al., 2019).

Participant 8: “*The only thing I have a problem with the doctors is that they give medication without checking for his blood levels. Michael is on high blood pressure medication. I think doctors must regularly check the person’s blood pressure and just not give medication*”.

Participant 9: “*Back in the day upon discharge family members were called in and the psychologists and social workers would discuss with the caregivers how to take care of the persons. But these days you will just see the person is discharge without any notice. You just see them here (*home*) with the card and medication. Our training was very different from this new training the people get.*

We had a good security system. These securities are just sleeping even when a patient runs away they don’t run after them”.

- ***Unhygienic Settings***

Furthermore, participants shared their experiences on the hygiene of the hospital.

Participant 6: “*The hospital is no longer what is used be like. In the 70s and 80s the hospitals were clean and neat you even wanted to be hospitalised even if you were not sick just so that you can experience it. But now it’s a different story*”.

Participant 9: “*The hospital used to be clean*”.

- ***Positive Experiences***

Despite the unpleasant experiences, some participants reported positive accounts as well.

Participant 6: "*I'm grateful for the service because if they didn't provide us with medication we wouldn't be here*".

Participant 8: "*I don't have a problem with the hospital".*

Participant 9: "*I was wondering if we can't pay a small fee like N$4 if you have to help the government because these drugs are expensive*".

The conflicting accounts of participants in relation to their experiences with health care providers have previously been identified by other scholars in their studies with caregivers. According to Riley-Mchugh et al. (2016), caregivers in their study reported mixed-emotions, such as fear and relief in their encounters with service providers. To substantiate the contrasting experiences of service providers, Veltman et al. (2002, p. 110) note that all caregivers in their study at some juncture experienced both positive and negative feelings, such as confusion, fear, love, sympathy, sadness, resentment, compassion. Thus it is safe to say that, experiences are personal even though there is a common thread among the majority of the participants in this present study indicating that service providers offer inadequate services.

4.3 The Intersection of Theoretical Framework and Participant's Experiences

4.3.1 Emotional Processes in a Nuclear Setting

It is evident throughout this analysis that participants were affected emotionally and physically in their role as caregivers. The subjective burden experienced by the caregivers in their role manifested through various emotions. Participants expressed feelings of worry, and fear, as well as anger and sadness because of the behaviour displayed by their ill relatives, which affected the participants psychologically. According to Milliken (2001), schizophrenia is a family illness that affects the caregivers and the rest of the family as much as it affects the patients. This speaks to the interdependence theory. Systemic theory posits that people are interdependent (Sels et al., 2016) therefore, what affects one person affects the rest of the family setting (Friedman, as cited in Bregman & White, 2011).

Furthermore, the objective burden also had its impact on the caregivers. The natural process of human beings is to care for those that are dependent on them. Since, schizophrenia is a disability illness, with high dependency on the caregivers; many caregivers had no choice but to care for their ill relatives. As a result, participants embodied the care role and in the process sacrificed their time, freedom and self-care for the betterment and well-being of their ill relatives. Milliken (2001) states that parent caregivers are mostly susceptible to severe burden because of their devotion to their children.

Although the participants in this present study were related to the ill relatives in various contexts, the burden experienced by participants was similar. Most participants experienced financial hardships and lack of formal and informal support, which means that they were all experiencing these challenges because of the human connectedness. Subsequently, this connection could not be separated because of the emotional connectedness that exists between human beings. Instead, participants developed resilience as many of them have accepted the condition of their ill relatives because of the realisation that they could not heal their ill relatives or change the situation.

According to Rachman (as cited in Howells, 2013) when people can successfully manage stressful live events and absorb the emotional disturbances associated with caregiving, it lessens the dysfunction in other areas of their life. However, this could not be said about all participants as some participants' quality of lives have been compromised physiologically due to the caregiving, which caused them to undergo ongoing medical attention to manage their own illnesses. This speaks to the circular causality concepts that postulate that, in order to understand family dynamics one has to look at the family as a whole because individuals in a family setting interact with each other including their actions (Kamal, 2014; Quesada, 1983). Therefore, it is safe to allude in this current study that physiological illness (high-blood pressure) is contributed by caring for people with schizophrenia, therefore, schizophrenia needs to be conceptualised in the manner of circular causality. Only then can context related interventions be helpful in ameliorating the burden experienced in each family.

CHAPTER 5

CONCLUSION

5.0 Introduction

This chapter presents a brief discussion of the main findings in relation to the assumptions of the study and how these findings answered the research questions. Additionally, the chapter provides recommendations based on the findings of the study and also addresses limitations and future research implications.

5.1 Conclusion

The primary objective of this study was to explore the lived experiences of caregivers for individuals diagnosed with schizophrenia. To achieve this objective, the researcher conducted face-to-face in depth interviews with nine participants using the purposive sampling method which had an inclusion criterion. Subsequently, the interviews were transcribed verbatim and thematic analysis was used to give a descriptive account of the caregivers' experiences.

The findings revealed that the majority of the participants were uninformed and unknowledgeable on the subject of schizophrenia. Many participants had no clear understanding of the diagnosis, although they understood the illness as a mental issue that needed medication to treat. Participants struggled to make meaning of the illness because even though their ill relatives were on treatment, the symptomology which is mostly disruptive behaviour was still pervasive in their ill relatives. This made it complicated for the participants to appreciate the illness as they felt helpless and hopeless in terms of recovery for their ill relatives'. As a result, their ability to provide quality care to their ill relatives was affected. The assumption of this research is that when caregivers are knowledgeable and informed about schizophrenia they are likely to better care for their ill relatives, which in turn will enhance their quality of lives as well as their ill relatives'.

Additionally, participants highlighted the burden they experienced in the course of their caregiving role. Participants experienced both subjective and object burdens, which impacted their lives mostly negatively. Participants' subjective burden was mostly associated with the odd destructive behaviours of their ill relatives that saw caregivers expressing feelings of worry, fear anger and depression. The objective burden felt by participants were largely financial hardship and food insecurity. This is perhaps because the majority of the participants was from poor socioeconomic background and was employed in low paying jobs. Although schizophrenia affects most caregivers globally, financially poor socioeconomic status seems to be trending among schizophrenia caregivers particularly, in the Arab, Asian and African context (Ae-Ngibise et al., 2015; Shamsaei et al., 2015; Suryani, 2015).

As if poverty was not burdensome enough, these participants also experienced lack of social support both in the informal and formal settings. As a result, many of them lived in isolation and struggled on their own as they only had themselves to rely on. This not only exacerbated the burden, but also affected their level of coping. In order to cope, many of participants relied on God or faith as a main coping mechanism, which according to Huang et al. (2008) is indicative of a lack of human connectedness. Since human beings are social beings, who are interdependent and interrelated, it is imperative that caregivers get as much support as they possibly can in order to enhance their resilience.

Furthermore, the relationship between health workers and the participants was found to be of a poor quality because participants felt dismissed and disregarded because they were excluded from the care and treatment plan of their ill relatives, even though they played a significant role in the lives of their ill relatives. Participants also felt that there was a lack of support and guidance from the health workers and that they were practically "learning on the job" – how to care for their ill relatives. This created a significant amount of burden and distress for participants as some participants expressed feeling of frustration with the service providers and health workers.

5.2 Reflection

During the data collection process, I realised that I was exposed to people with mental health conditions earlier in my childhood in the community I grew up in however, at the time I was unknowledgeable. It was during the BPsych program that this exposure was cemented as I became more aware and knowledgeable on the subject matter. The continuous visibility of people with mental illness who appeared uncared for intrigued me but also compelled me to investigate a psychiatric condition, hence this research. This study is more than creating new knowledge; it is about social change and advocating for people directly and indirectly affected by mental illnesses. It is my civic duty and social responsibility as a mental health professional to shed light on mental health challenges and to foster change where possible. As a result, I was intentional about gathering necessary information in the study that could be useful to propose for future interventions.

My experience in the field was humbling and welcoming. Participants were open and willing to invite me into their dwellings, and eager to share their personal stories without shame. I was honoured to listen and share in the experience of storytelling as it unfolded. It was evident that most participant needed professional help themselves in a form counselling. However, as a researcher I could not provide counselling but did allocate venting time during the introduction stage. Their concerns were mostly centred on the uncontrollable behaviours of their ill relatives, and the frustration and helplessness they felt because of a lack of information about schizophrenia. During the venting time, I was able to gather information that was useful to the study.

The challenge I experienced at times was detaching myself from the natural role of a therapist. However, reminding myself of the objective of a researcher kept me focus throughout. Nonetheless, the therapist role was helpful in building rapport and trust with participants early on and also helped in providing debriefing sessions and suggesting referral services. Another, challenge I experience was that participants wanted me to intervene and address their ill relatives on non-compliance to medication and unhealthy coping mechanisms. When this situation presented itself, I deferred the intervention to the end of the interview where I provided inclusive psycho-education to the participants and their relatives if they were present and willing. Of note, the field research also exposed me to lived experiences of participants in real-time and not only through story telling as there was an incident where the participant and I went threatened by an ill relative.

The field experience also reminded me of gratefulness. As I witness participants' living circumstances I was reminded of my privileges. Some of them had no electricity, or the living space was small, and sometimes the environment was unhygienic. Most of them were experiencing food insecurity. I felt guilty for not offering practical support to the participants. I remember going home after these interviews feeling emotionally, physically and spiritually drained. At times I cried about the injustices and the level of poverty I witness. Journaling and debriefing sessions with my classmates helped to continue with the research.

Despite the challenges, the process was empowering as I witnessed the resilience, and endurance participants showed in dealing with their ill relatives. Despite the difficulties, participants actually want to live and care for their ill relatives. Caregivers actually see the whole person and not only the illness. They would reminisce on the pleasant memories of the ill relative when they were functioning optimally and even shared pictures of their loved ones at their best moments. I could see and hear the hope and despair simultaneously of wanting better for their ill relatives, and how information and knowledge about schizophrenia could be helpful for them. For those who requested help for food parcels where directed to respective offices and organisations. It is my hope that this research will have a lasting impact.

5.3 Limitations of the Study

The objective of this research was to explore the experiences of people in caregiving roles for patients diagnosed with schizophrenia. Due to the chosen research design, which was a qualitative approach, the study utilised a small sample size which only comprised of participants residing in Windhoek. Therefore, the findings of this study cannot be generalised to the larger population as it is not representative of most caregivers in the Namibian context or experiences. However, the findings could be utilised either as a hypothesis or to gauge caregivers’ experiences in dealing with other mental illnesses. Another challenge that was experienced in the course of conducting this study was the language barrier. Most caregivers were not proficient in the English language. As a result, the researcher used Afrikaans and Khoekhoe-gowab to conduct some of the interviews. Hence, it may be that nuances of the experiences of the caregivers may have been lost in the translation process and ultimately the interpretation process, as the languages used for the interviews do not have the vocabulary for certain psychological terms.

5.4 Recommendations

The recommendations made for this study are based on the personal experiences and suggestions made by the participants.

5.4.1 Psycho-Education

Participants in this study indicated that their burden was exacerbated by their lack of information and knowledge about schizophrenia. They expressed that they lacked general information about the illness, such as the diagnosis, behaviour, causality and prognosis. They also expressed having difficulty to get compliance from their ill relatives in taking their medication and that they also lacked requisite skills to provide quality care to their ill relatives. Psycho-education programmes are found to be successful in the reduction of relapse rates of patients. However, in this context family based psycho-educative programs that health workers can facilitate at the Mental Health Unit seem to be desirable among caregivers. So that every member involved in the caregiving process can be empowered on how to manage the ill relative. Also when information is cascaded downwards to the primary users, it needs to be done in simple language that is easily understood by caregivers. Therefore, having diverse staff members at the Mental Health Unit is crucial in order to meet caregivers' needs. Alternatively, information can be provided in a leaflet form in all local languages. Studies have shown that when caregivers are educated and informed about the illness and supported that those in their care have a better prognosis (Evans, 2009).

5.4.2 Relationship with Mental Health Professionals

All the participants in this study felt that the mental health professionals disregard their role as caregivers and they tend to exclude them in the treatment plan and execution process for their ill relatives. Participants were clamouring to be actively involved in all the steps involved in the treatment of the ill relatives because they play a vital part in the well-being of the ill relatives. The mental well-being of the ill relatives appeared to have a bearing on the health of the caregivers. When the ill relatives were not doing well, the health and well-being of caregivers tended to be compromised as well. Hence, it is recommended that health workers not only engage the ill relatives, but also involve the caregivers when they accompany their ill relatives. It is recommended that health workers be pro-active in including caregivers through undertaking follow-up telephonic calls once a month or to invite them to physically report to the facility for face-to-face conversations to enquire about the progress or lack thereof, of the ill relatives as well as the well-being of the caregivers.

5.4.3 Financial and Food Support

Most of the participants reported that they were experiencing financial difficulties and food insecurity. Caregivers expressed that they could benefit from Harambee food parcels to supplement the feeding of their ill relatives. The provision of adequate of food is of vital importance because most patients with schizophrenia need to eat before taking their medication and they also tend to eat more frequently and require larger portions compared to the general population. To reduce the food insecurity, it is perhaps helpful to encourage setting up community programs such as vegetable garden projects. Although Namibia is one of the few countries on the continent that provides disability grants to mentally ill people, the amount is not sufficient to cover all the basic needs of the patients and the caregivers.

5.4.4 Support Groups

Caregivers also expressed that they could benefit from support groups where they could come together and share their challenges and experiences with others who are in similar situations. Support groups are known to instill hope and create universality in group settings as they make individuals feel that they are not alone in their suffering as they share their experiences with others and also get empowered in the process. Health workers can set up support groups for caregivers at the Mental Health Unit which they can run on a biweekly basis, and later on train some caregivers to run peer support groups in their local communities. This will, especially, be useful considering that most of the caregivers were not aware of the counselling services provided at the Mental Health Unit, therefore, none of them were accessing these services. Health workers have a professional responsibility of edifying those that are under their care.

5.4.5 Community-Based Mental Health Centres

Many caregivers had reservations about the Mental Health Unit because of the environment of the wards and the treatment their loved ones are subjected to. Hence, they expressed preference to stay with their sick relatives instead of having them hospitalised. However, caregivers suggested that they would be more willing to leave their mentally sick relatives at community health facilities/centers operated and run by trained professionals. Such community centres must be humane and user-friendly and should be able to assist them to manage their ill relatives on a short term basis, especially, when the mentally ill relatives are experiencing psychosis or have relapsed due to non-adherence with medication. The centres can also comprise a wing for practical vocational skills, such as gardening projects that will empower the patients, and simultaneously serve as recreation centres where outpatients too can come for sport activities. Caregivers, themselves expressed their willingness to get involved in running small tasks at the centres.

5.5 Future Research

This study was basically a foundation for exploring caregivers' experiences. As much as it shed light on challenges experienced by caregivers, it also identified various caregiver groups in relation to the relationship with the patients. Additionally, although there were similarities in experiences across different ethnic groups, the nuances may have been lost in the translation of language. Therefore, future research can either focus on the experiences of a specific care group, for example, sibling caregivers or parent caregivers or spousal caregivers to highlight the needs specific to that group. Studies that were conducted in other contexts and have focused on sibling- carers indicated different needs compared to the needs of parent carers or spousal experiences.

Additionally, ethnographic studies with specific ethnic groups may be useful in capturing the nuances of the experiences, which may have been lost in this study, as people express themselves better in their native languages. People also tend to be more open when they can relate with the researcher as they may feel better understood. In this study, the researcher experienced that the Damara/Nama and some Afrikaans speaking participants were more open in articulating their experiences compared to other ethnic groups. This is perhaps because of the language proficiency and the relatedness the Damara/Nama participants felt with the researcher

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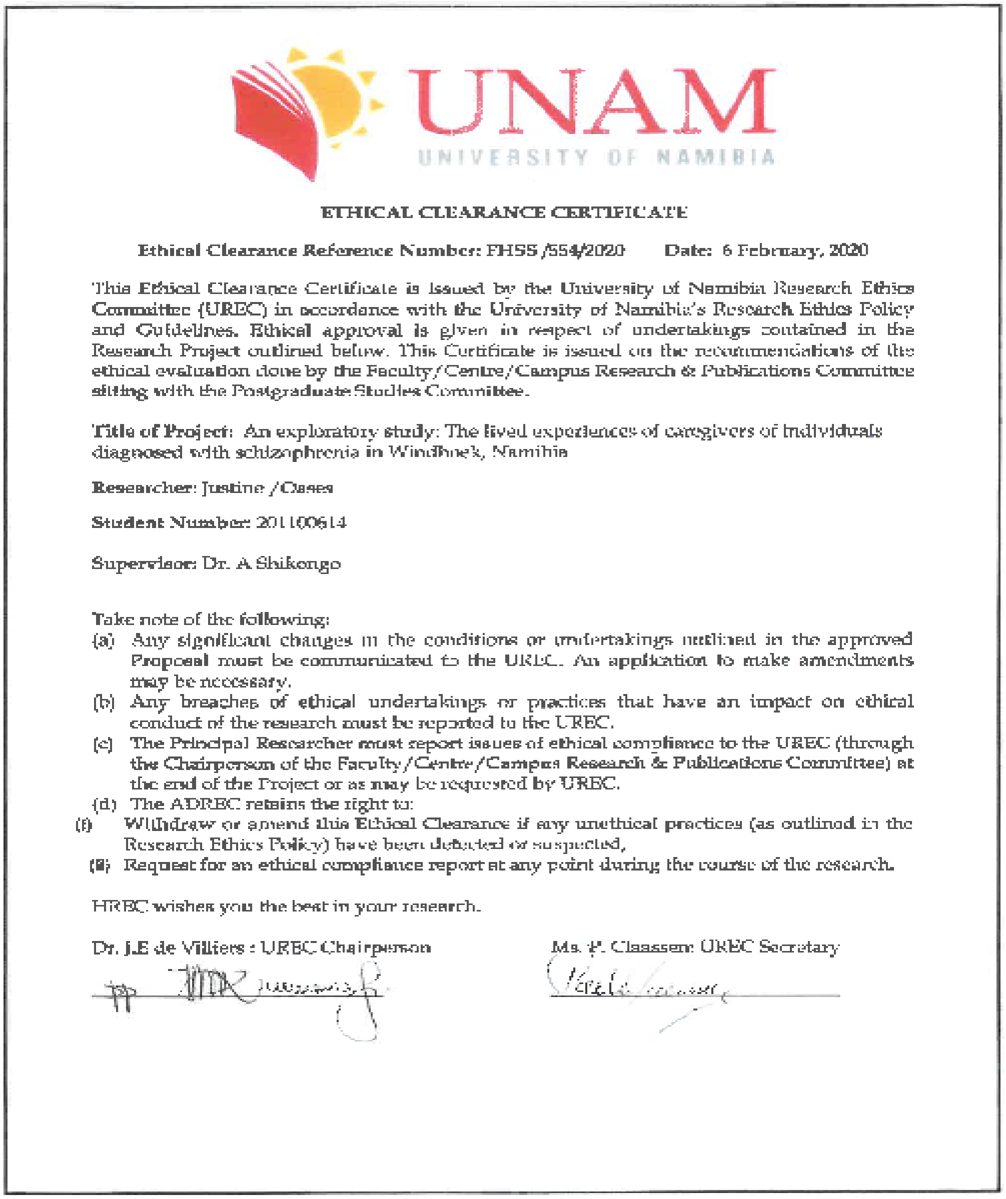
APPENDICES

APPENDIX A: ETHICAL CLEARANCE CERTIFICATE



UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: FHSS /554/2020 **Date:** 6 February, 2020

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: An exploratory study: The lived experiences of caregivers of individuals diagnosed with schizophrenia in Windhoek, Namibia

Researcher: Justine /Oases

Student Number: 201100614

Supervisor: Dr. A Shikongo

Take note of the following:

(a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
(b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
(c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
(d) The ADREC retains the right to:
(i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
(ii) Request for an ethical compliance report at any point during the course of the research.

HREC wishes you the best in your research.

Dr. J.E de Villiers : UREC Chairperson

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Ms. P. Claassen: UREC Secretary

APPENDIX B: RESEARCH PERMISSION REQUEST LETTER MoHSS

2032019

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Received
28 AUG 2018

UNAM
UNIVERSITY OF NAMIBIA

Ms Justine /Oaes
P.O. Box 232384
Windhoek, Namibia
Cell: +264 814844801
Email: maidoaes@gmail.com
28 August 2018

Chief Medical Superintendent
Ministry of Health and Social Services
Windhoek Central Hospital
Private Bag 13215
Windhoek
Namibia

<u>Request for Permission to Conduct Interviews with Relatives of Mental Health Patients</u>

Dear Sir/ Madam

I am Justine /Oaes a first year Masters student in Clinical Psychology, at the University of Namibia, student number 201100674. I hereby, wish to request your permission to conduct interviews with relatives of mentally ill patients to assist with my Master's Thesis.

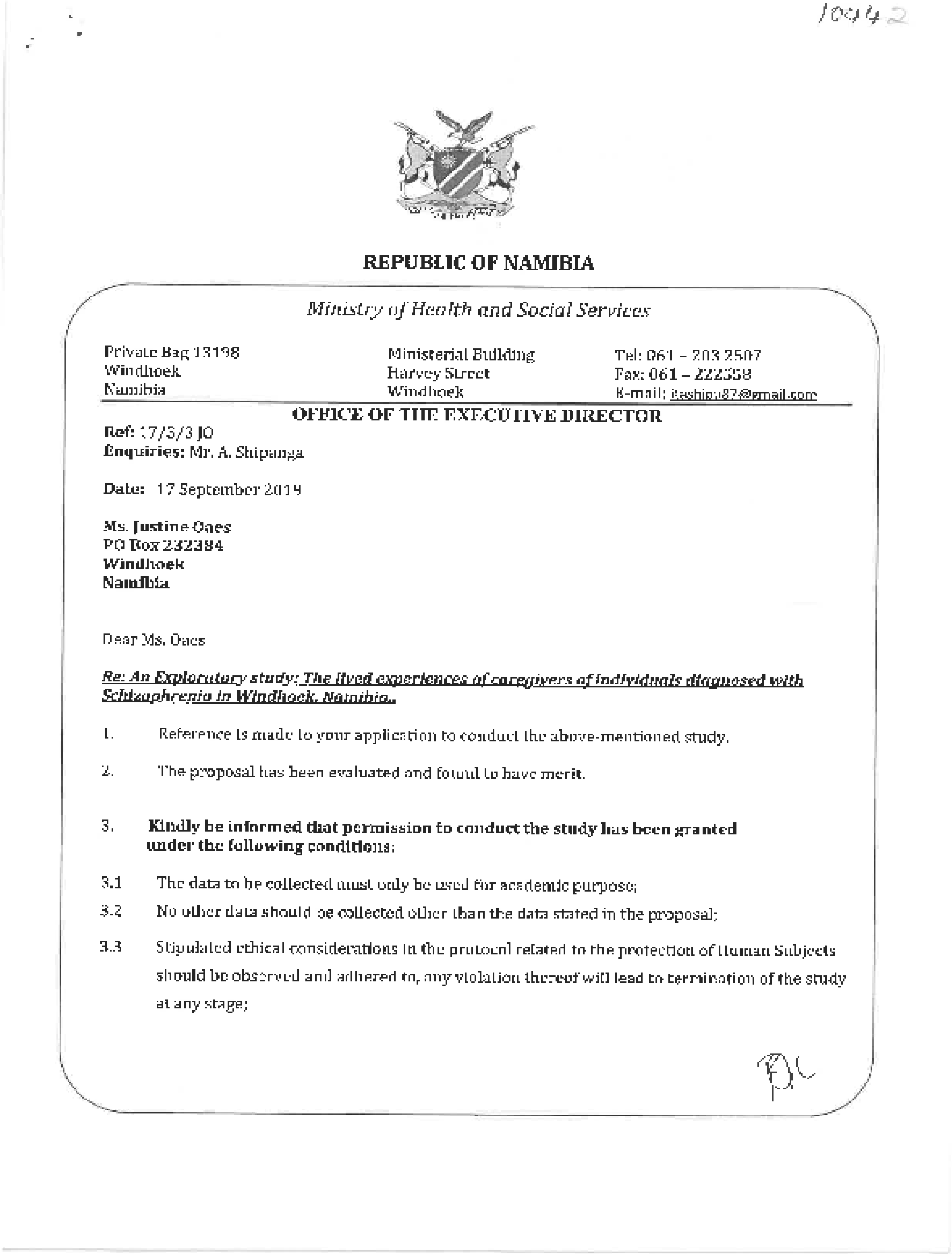
My thesis is interested to explore experiences of family members who have a relative diagnosed with schizophrenia. Currently, there is limited academic work in general on mental health issues in the Namibian context, more so on schizophrenia. Therefore, I would appreciate your assistance in this matter as it will benefit the Mental Health Fraternity as a whole, the Academic Community of University of Namibia Psychology Department as well as the society at large.

I am fully aware of the sensitivity and ethical issues surrounding such research but can also not stress enough the relevance and importance of this study. Hence, the sample will exclude the patients themselves and will only focus on relatives who are willing to participate. If necessary, therapy in the form of debriefing will be provided for the family members to manage any triggers that might arise due to the study.

Thank you in advance for your assistance.

Yours sincerely
Justine Oaes (student)

APPENDIX C: MoHSS RESEARCH APPROVAL LETTER



10942

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 – 203 2507
Fax: 061 – 222558
E-mail: ikashipu87@gmail.com

OFFICE OF THE EXECUTIVE DIRECTOR

Ref: 17/3/3 JO
Enquiries: Mr. A. Shipanga

Date: 17 September 2019

Ms. Justine Oaes
PO Box 232384
Windhoek
Namibia

Dear Ms. Oaes

Re: An Exploratory study: The lived experiences of caregivers of individuals diagnosed with Schizophrenia in Windhoek, Namibia..

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

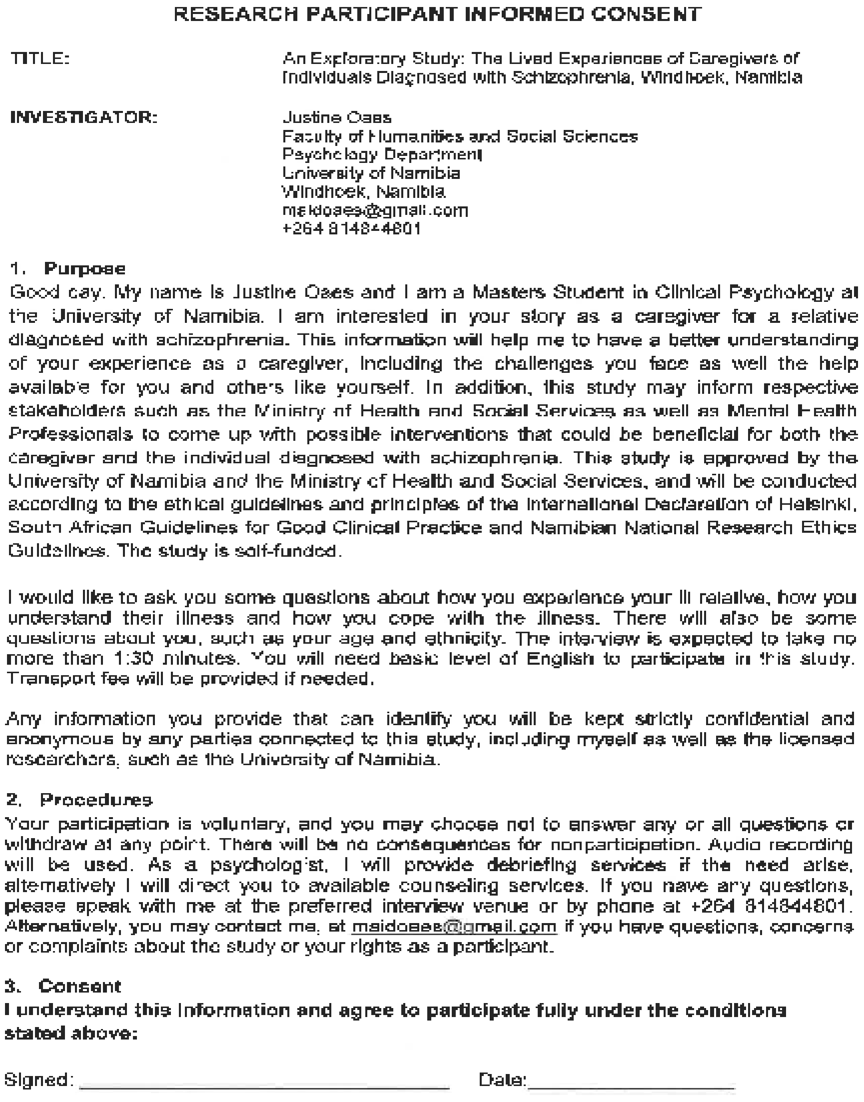
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**

3.1 The data to be collected must only be used for academic purpose;

3.2 No other data should be collected other than the data stated in the proposal;

3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;

APPENDIX D: PARTICIPANT INFOMRED CONSENT LETTER



RESEARCH PARTICIPANT INFORMED CONSENT

TITLE: An Exploratory Study: The Lived Experiences of Caregivers of Individuals Diagnosed with Schizophrenia, Windhoek, Namibia

INVESTIGATOR:
Justine Oaes
Faculty of Humanities and Social Sciences
Psychology Department
University of Namibia
Windhoek, Namibia
maidoaes@gmail.com
+264 814844801

1. Purpose

Good day. My name is Justine Oaes and I am a Masters Student in Clinical Psychology at the University of Namibia. I am interested in your story as a caregiver for a relative diagnosed with schizophrenia. This information will help me to have a better understanding of your experience as a caregiver, including the challenges you face as well the help available for you and others like yourself. In addition, this study may inform respective stakeholders such as the Ministry of Health and Social Services as well as Mental Health Professionals to come up with possible interventions that could be beneficial for both the caregiver and the individual diagnosed with schizophrenia. This study is approved by the University of Namibia and the Ministry of Health and Social Services, and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and Namibian National Research Ethics Guidelines. The study is self-funded.

I would like to ask you some questions about how you experience your ill relative, how you understand their illness and how you cope with the illness. There will also be some questions about you, such as your age and ethnicity. The interview is expected to take no more than 1:30 minutes. You will need basic level of English to participate in this study. Transport fee will be provided if needed.

Any information you provide that can identify you will be kept strictly confidential and anonymous by any parties connected to this study, including myself as well as the licensed researchers, such as the University of Namibia.

2. Procedures

Your participation is voluntary, and you may choose not to answer any or all questions or withdraw at any point. There will be no consequences for nonparticipation. Audio recording will be used. As a psychologist, I will provide debriefing services if the need arise, alternatively I will direct you to available counseling services. If you have any questions, please speak with me at the preferred interview venue or by phone at +264 814844801. Alternatively, you may contact me, at maidoaes@gmail.com if you have questions, concerns or complaints about the study or your rights as a participant.

3. Consent

I understand this information and agree to participate fully under the conditions stated above:

Signed: ______________________________ Date:_______________

APPENDIX E: PARTICIPANT RECRUITMENT LETTER

RESEARCH PARTICIPANT RECRUITMENT LETTER

Title: An exploratory study: The Lived Experiences of Caregivers of Individuals Diagnosed with Schizophrenia in Windhoek, Namibia

Dear esteemed participants,

My name is Justina /Oaes. I am a Masters in Clinical Psychology student at the University of Namibia, student number 201100614. As part of my studies, I have to complete a mini-thesis in partial fulfilment for my degree and therefore, humbly request your participation in this study.

Purpose of the Study:

Research indicates that more and more family members have become caregivers for their mentally ill relatives diagnosed with schizophrenia due to the current trend of deinstitutionalization. As a result, caregivers struggle to cope psychologically and express feelings of being burdened, additional to the financial and physical stressors such as missing work as they have to attend to their ill relative.

The main aim of this research study is to explore the experiences and challenges that you as a caregiver face. For example, how do you understand and make meaning of the illness of your relative, what support systems are available for you and how do you cope with the illness.

The information gathered from your experiences may inform respective stakeholders such as the Ministry of Health and Social Services as well as the Mental Health Professionals on possible interventions that could be beneficial for both you the caregiver and the individual diagnosed with schizophrenia.

Participant's role:

Your participation is voluntary and you may withdraw from the study anytime you wish to. You will be requested to give permission to take part in this study and thus to sign a consent form. The information provided by you will remain confidential and your identity will not be disclosed to anyone. Information will be collected through one-on-one in-depth interviews which will be recorded via an audiotaped with your permission.

The interview is expected to take not more than 2 hours. You will need basic level of English to participate in this study. The interview will be conducted at a venue that suits the participant best and a transport fee will be provided if needed.

Should you have any questions or require clarification about this study please feel free to contact me or my supervisor. Counselling services will also be provided if need be.

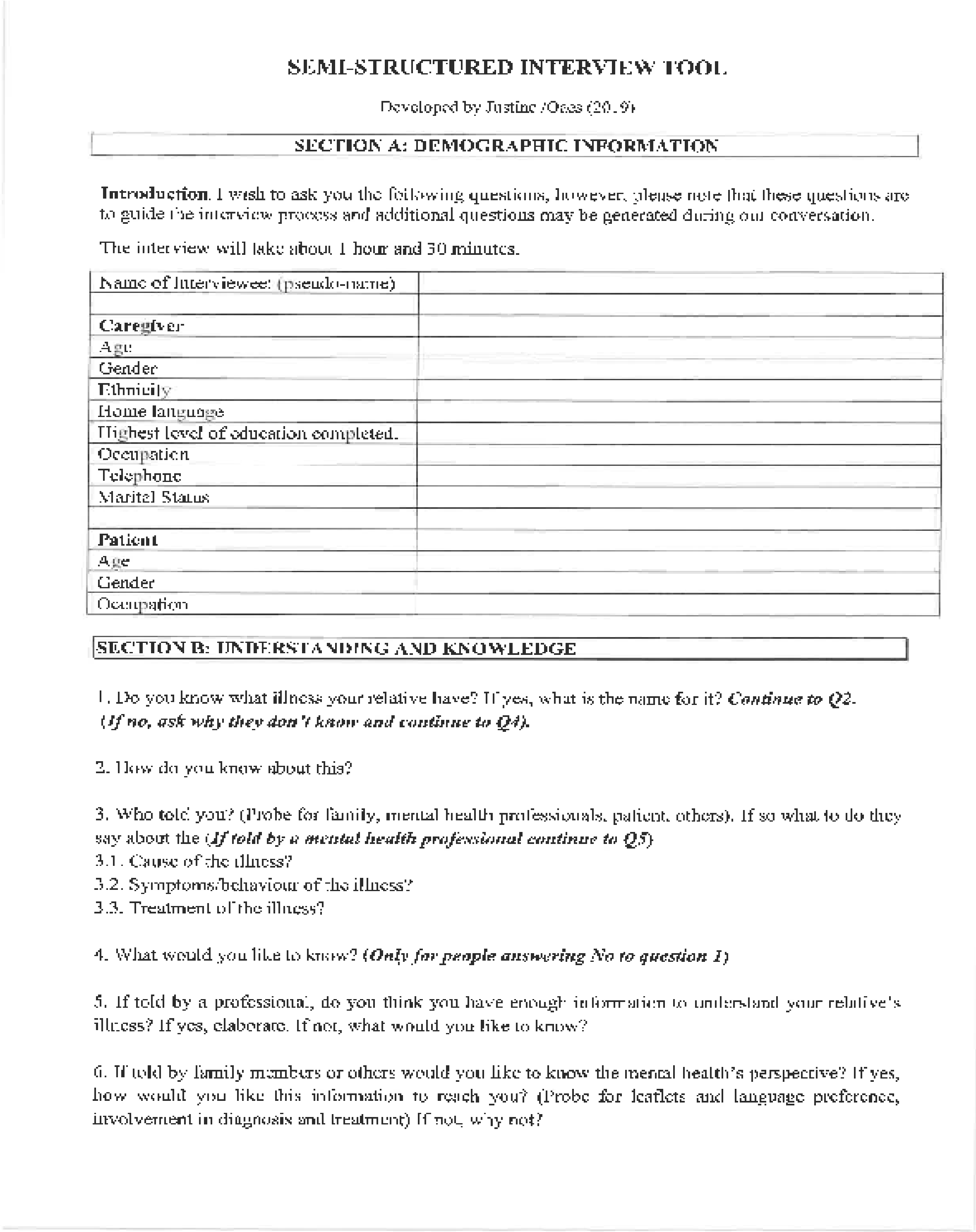
Thank you in advance for your participation. It is highly appreciated.

Yours sincerely,

Ms. Justina /Oaes
MA Clinical Psychology Student
Email: msidoaes@gmail.com.na
Contact: +264814844801

Dr. A. E.B-Shikongo
Research Supervisor
Email: ashikongo@gmail.com
Contact: +264814790991

APPENDIX F: INTERVIEW TOOL



SEMI-STRUCTURED INTERVIEW TOOL

Developed by Justine /Oses (2019)

SECTION A: DEMOGRAPHIC INFORMATION

Introduction. I wish to ask you the following questions, however, please note that these questions are to guide the interview process and additional questions may be generated during our conversation.

The interview will take about 1 hour and 30 minutes.

Name of Interviewee: (pseudo-name)	
Caregiver	
Age	
Gender	
Ethnicity	
Home language	
Highest level of education completed.	
Occupation	
Telephone	
Marital Status	
Patient	
Age	
Gender	
Occupation	

SECTION B: UNDERSTANDING AND KNOWLEDGE

1. Do you know what illness your relative have? If yes, what is the name for it? ***Continue to Q2.***
(If no, ask why they don't know and continue to Q4).

2. How do you know about this?

3. Who told you? (Probe for family, mental health professionals, patient, others). If so what to do they say about the ***(If told by a mental health professional continue to Q5)***
3.1. Cause of the illness?
3.2. Symptoms/behaviour of the illness?
3.3. Treatment of the illness?

4. What would you like to know? ***(Only for people answering No to question 1)***

5. If told by a professional, do you think you have enough information to understand your relative's illness? If yes, elaborate. If not, what would you like to know?

6. If told by family members or others would you like to know the mental health's perspective? If yes, how would you like this information to reach you? (Probe for leaflets and language preference, involvement in diagnosis and treatment) If not, why not?