

**THE CULTURAL BELIEFS OF PARENTS AS CAREGIVERS OF
ADULT CHILDREN LIVING WITH SCHIZOPHRENIA IN A RURAL
AFRICAN COMMUNITY**

by

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DECLARATION

I hereby declare that “The cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community” is my own work, that all the sources used or quoted have been indicated and acknowledged by means of a complete list of references, and that this dissertation was not previously submitted by me for a degree at another University.

Signature

Date:

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ABSTRACT

THE CULTURAL BELIEFS OF PARENTS AS CAREGIVERS OF ADULT CHILDREN LIVING WITH SCHIZOPHRENIA IN A RURAL AFRICAN COMMUNITY

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The integration of mental health services into primary health care and the shift toward community- and family-based care for people with chronic mental disorders have been widely advocated globally (Breen, Swartz & Flisher, 2009:327). This resulted in people with mental illnesses staying within their communities during their recovery, accessing care mainly from their family members and secondarily from health care professionals within communities. Families predominantly relied on cultural African explanations for disease and illness, which usually motivated the choice of treatment options (Curationis, 2002). Unfortunately, most clinicians are not adequately trained to understand how culture influences the clinical manifestation of mental disorders (Breen et al., 2009:327). This sometimes results in people consulting African healers who are considered to understand illnesses much better. It is for the above-mentioned reasons that the study seeks to explore the cultural beliefs of parents as caregivers of adult children living with schizophrenia. The study is expected to extract insightful information regarding the cultural beliefs in relation to mental illness to promote a better understanding of the phenomenon within the African cultural sphere.

The goal of the study was to explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a community day care centre in

Klipgat. The data was collected through non-probability purposive sampling. Rich, in-depth data was collected through semi-structured interviews from a random sample of 12 participants selected from the enrolment list of attendees at Mfihlakalo Day Care Centre.

The research findings indicate that there is an evident existence of cultural beliefs that perceive the cause of mental illnesses, especially schizophrenia, as birth complications, communication from ancestors, witchcraft or stress. Mental health care users are as a result excluded from society and labelled as aggressive and abnormal. The families of mental health care users have a positive perception of their family members living with mental illness, regarding them as special people suffering from natural diseases, birth complications, and lack of nurturing.

The research study concludes that even though the communities have negative perceptions of mental illnesses, the situation has vastly evolved through the years. Educational and awareness strategies have played a role in educating families and communities about mental illnesses, although the exposure has been noted as minimal. The research study suggests strong and effective psycho-educational programmes and support to promote knowledge empowerment and insight with regard to mental illness. Additionally, transparency regarding mental illness to reduce the stigma of those living with mental illness and their immediate families, in turn promoting social inclusion.

KEY WORDS

African

Culture

Beliefs

Cultural beliefs

Caregivers

Schizophrenia

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CHAPTER ONE –

GENERAL INTRODUCTION AND ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Mental illnesses affect humans across all cultures. Schizophrenia is a form of mental illness characterised by a broad spectrum of cognitive and emotional dysfunctions, including delusions, hallucinations, disorganised speech, and inappropriate emotions (Barlow & Durand, 2009:467). The World Health Organization (WHO, 2011) stipulates that mental illnesses among Africans are changing because of environmental factors such as culture and structural developments. Mental health challenges affect people across all cultures. Africans are highly affected by mental health challenges, though these groups rarely access treatment.

In South Africa, deinstitutionalisation resulted in families becoming the main providers of care, with health care professionals playing a secondary role (Mavundla, Toth & Mphelane, 2009:360). Therefore, informal family caregivers have become the primary persons involved in the wellbeing of individuals with mental illnesses. The caregivers and persons living with mental illnesses have access, though limited, to community-based primary health care services where they are able to seek psychiatric treatment and collect psychotropic medication (Mavundla et al., 2009:360).

The main reason for lack of access to mental health treatment among Africans is that the rationale for the origin of mental illnesses is based initially on witchcraft or spirit possession (Labuschagne, Bekker & Boonzaaier, 2003:107). Mental illnesses among Africans present itself in the form of dreams, voices or visual messages that can only be seen or heard by the person whom the message is sent to. The person mumbles, speaks to himself/herself, and/or sees things that others cannot see, thus leading to Western explanations of hallucinations or delusions, then a diagnosis of schizophrenia (Labuschagne et al., 2003:107). This leads to Africans consulting with sangomas and traditional healers, as they are thought to have the authority to communicate with the

ancestors or to cure mental illnesses caused by witchcraft by appeasing the ancestors through specific rituals (Makau, 2003:08).

The integration of mental health services into primary health care and the shift toward community- and family-based care for people with chronic mental disorders have been widely advocated globally (Breen et al., 2009:327). Cultural causal factors are amongst the identified causes of mental illnesses, thus understanding the cultural dimensions underlying a patient's mental health is critical to the successful outcome of a clinical encounter. Unfortunately, most clinicians are not adequately trained to understand how culture influences the clinical manifestation of mental disorders (Breen et al., 2009:327). Therefore the cultural beliefs of parents as caregivers of adult children living with a mental illness, specifically schizophrenia, were explored. The researcher is of the opinion that the effectiveness of a diagnosis depends on a clear understanding of the cultural dimensions the patient believes in. An understanding of the cultural dimensions assists in understanding the factors that influence the key caregiver's decision-making processes.

In the South African context, cultural approaches are the strategic plans used by Africans to explain and address a mental illness, which to them is significant as it is tradition to follow the guidelines of their culture (Mavundla et al., 2009:358). Mental illness is viewed as a complex area that can be addressed in different ways. Failure to explore all the treatment options can result in low success rates in terms of recovery and management (Curationis, 2002:46).

After the democratisation of South Africa in 1994, the health care system was reorganised in accordance with the primary health care philosophy advocated by the World Health Organization (WHO). This was accompanied by a process of deinstitutionalisation of mental health care services, which has led families to become the main providers of care to individuals with mental illnesses (Mavundla et al., 2009:358).

Du Plessis (2002:121) proposes that every community constructs its own reality about itself. This reality and the meanings that people give their experiences are culturally and socially constructed. The researcher is of the opinion that the beliefs people hold with regard to mental illness, specifically schizophrenia, are constructed by the community's culture. It is for the purpose of this study that the researcher explored the cultural beliefs of parents as caregivers of adult children living with schizophrenia.

The following are definitions of key concepts utilised throughout the study:

- **African**

Oxford dictionary (2016) defines an "African" as native person from Africa, especially a black person. In the context of this study, an African refers to black South African citizens.

- **Culture**

Culture refers to the customs, habits, skills, technology, arts, values, ideology, science, and religious and political behaviour of a group of people in a specific time period (Barker, 2003:105). Culture is further stipulated as a set of norms and values that guide a community. Behaviour is shaped by cultural norms and values, therefore culture in the context of the study refers to the learnt norms, beliefs and attributed values that people attach to mental illness in rural communities.

- **Beliefs**

Donald's Medical Dictionary (2010:120) defines beliefs as something one accepts as true or real; a firmly held opinion. It also involves trust, faith, or confidence in someone or something. In the context of the study, beliefs are those aspects that a community hold true to themselves.

- **Cultural beliefs**

Cultural beliefs are defined by Matthews (2010:02) as a set of shared norms, standards and expectations by a specific group of individuals. These norms and standards are used to explain certain human behaviours and life circumstances. In the context of this study, cultural beliefs refer to belief systems held by parents as caregivers of adult children living with schizophrenia with regard to what they perceive to be the cause of schizophrenia.

- **Caregivers**

Barker (2003:92) defines a caregiver as one who provides for the physical, emotional and social needs of another person, who is often dependent on the caregiver and cannot provide for his/her own needs. Caregivers can be parents, relatives, day care workers, or health care specialists. Within the context of this study, parents are referred to as caregivers of adult children living with schizophrenia.

- **Schizophrenia**

Schizophrenia is a disorder characterised by a broad spectrum of cognitive and emotional dysfunctions, including delusions, hallucinations, disorganised speech, and inappropriate emotions (Barlow & Durand, 2009:467). A diagnosis of schizophrenia is ruled out by a qualified health care professional following the guidelines of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). People living with schizophrenia possess characteristics such as hearing voices and seeing things that are not visible to others.

1.2 THEORETICAL FRAMEWORK

It is notable that human beings have specific personal beliefs attached to experiences in their lives. Such beliefs are shaped by values, norms and standards set by cultural, environmental, or societal connotations and used to explain human behaviours and

actions. This is evident in explaining health behaviours and choices undertaken by individuals in their specific life settings (Matthews, 2010:46). It is common knowledge that human beings strive for security in all aspects of human life, including health security. The need for health security arises from individuals perceiving themselves as vulnerable to contracting certain diseases. This results in individuals being motivated to take action against contracting the perceived disease or managing the already contracted disease (Brieger, 2006:48).

Africans living in rural communities are considered to be traditional people who are influenced by cultural beliefs with regard to explaining human behaviour. Cultural belief systems shape their reality and provide explanations for human behaviour within their life settings. Aspects such as causes of diseases, contraction of diseases, and management and control of diseases are highly influenced by cultural belief systems attached to illness (Makau, 2003:09). It is therefore of importance to note that the choice of the Health Belief Model was deemed applicable for the conducted study as it explains health behaviour as influenced by personal perceptions and belief systems (Jones & Bartlett, 2004:12). The Health Belief Model guided the researcher in exploring the link between cultural beliefs and schizophrenia as experienced by parents who are caregivers to their adult children living with schizophrenia in a rural African community.

The Health Belief Model is constructed with the aim of explaining and predicting preventative health-related behaviours in terms of certain belief patterns (Brieger, 2006:48). The Health Belief Model is based on the underlying concept that health behaviour is determined by personal beliefs or perceptions about a disease, thus leading to different approaches to reduce the incidence of the disease (Jones & Bartlett, 2004:14).

Brieger (2006:51) specifies that the basic assumptions of the Health Belief Model inform that the perception of a health threat is itself influenced by three factors, namely the interest and concern about health, specific health beliefs about vulnerability to a

particular health threat, and beliefs about consequences of a health problem. These three factors constitute the general health values attached to illness.

Jones and Bartlett (2004:14) assert that the four main components of the Health Belief Model include perceived susceptibility, perceived seriousness, perceived benefits of taking action, and perceived barriers to taking action. Taylor, Bury, Carter, Garfield, Neuwould and Rennie (2007:133), Lizewski (2010:454), Rabkin and Ramien (2001:209), along with Brieger (2006:48) add three more components of the Health Belief Model which have been identified throughout the advancement and refinement of the model, namely cues to taking action, motivating factors, and self-efficacy. The components of the Health Belief Model are discussed below.

- **Perceived susceptibility**

Perceived susceptibility explains the possibility of one contracting the disease at various degrees (Jones & Bartlett, 2004:16). Each individual has their own perception of experiencing a condition that would adversely affect their health. Individuals make a judgment about the risk of contracting a disease. Taylor et al. (2007:210) assert that those at the low extreme deny the possibility of contracting the disease; those at the moderate extreme admit the possibility of contracting the disease; and those at the high degree perceive the danger of contracting the disease. A person's belief of being at risk of contracting a disease motivates and encourages the desired action to be taken to reduce the possibility of contracting the disease (Rabkin & Ramien, 2001:112). Perception of increased susceptibility is therefore beneficial as it encourages healthier behaviours.

The Health Belief Model is linked to health-related behavioural patterns of those living with mental illness in rural African communities. Africans believe that mental illness is a type of gift or communication from the ancestors which is inherently transferred from generation to generation, thus creating a sense of susceptibility within the surviving family members (Makau, 2003:08). It has been noted that from an African point of view, these gifts are transferred through a

process called spirit reincarnation whereby a deceased family member's spirit finds life in a surviving family member. Furthermore, the gift of "the calling" to be a sangoma is also inherited through the spirit whereby the next chosen sangoma within the surviving family members would be contacted by the deceased ancestor who was a sangoma. This ancestor is reported to give orders to the chosen family member through dreams (Jong, 2003:33).

Surviving family members of deceased individuals who were sangomas or of families that strongly believe in cultural belief systems have a high level of susceptibility. Surviving family members judge there to be a great risk of contracting the disease (Jones & Bartlett, 2004:19), because the transference of gifts will inevitably be expected within these families, with first degree relatives being at higher risk. The families are then motivated to take action about the condition. Actions taken could include seeking treatment or consulting with traditional healers to get clearance on who will be the next "chosen one". In cases where the visions are already being experienced, consultation with traditional healers would be considered for dream interpretations because only traditional healers are believed to have the special ability to connect with ancestors (Curationis, 2002:222).

- **Perceived seriousness**

Perceived seriousness or severity of a condition explains the beliefs a person holds concerning the effects a given condition can have on their lives. It is usually based on medical knowledge and information about the condition or on personal beliefs about the condition (Lizewski, 2010:456). Taylor et al. (2007:22) argue that individuals explore the impact of the perceived condition in their lives. This would include the impact the condition would have on their overall lifestyle, such as social, relationship and occupational abilities.

Within the context of the study, parents as caregivers would explore the impact of the seriousness of schizophrenia on their adult children and also on their own

lives as caregivers. This would include an exploration of parents' lifestyles as caregivers, as the caregiving responsibilities vary according to the severity of the condition. Arguably, some of the challenges experienced by parents as caregivers of adult children living with schizophrenia as noted by Roberto and Jarrot, (2008:102), Ivey, Laditka, Price, Tseng, Beard, Liu, Ffterman, Wu and Logsdon (2012:807), Butler (2008:1260), and Potgieter and Heyns (2006:548) include financial, social, physical, and emotional challenges due to the severity of schizophrenia suffered by their adult children. It therefore makes sense that parents as caregivers would explore the perceived seriousness of their adult children's schizophrenia so that they can evaluate the level of impact on their families and changes that need to occur, as the disorder does not only affect those living with it, but also their families.

- **Perceived benefits of taking action**

The perceived benefits of taking action explain actions taken towards the prevention of diseases or dealing with diseases. This is the next step after accepting the susceptibility and seriousness of the condition (Taylor et al., 2007:22). The perceived benefit of taking action is motivated by the belief that the new behaviour will offset the development and manifestation of the disease. The positive benefit of the behaviour is therefore influenced by the individual's personal beliefs and overall health motivation rather than factual evidence (Jones & Bartlett, 2004:23).

The human instinct to take action against specific behaviours is motivated by a desire for a less painful and more comfortable lifestyle. In African cultural contexts, it is argued that failure to take action or orders as prescribed by the ancestors results in punishment from these ancestors. Punishment might take the form of a long-term incurable chronic illnesses and a series of misfortunes. Misfortunes are regarded as bad luck or having a bad omen around one's head, which results in continuous occurrences of accidents and loss. Women in such cases might fail to conceive. These challenges can only be cured by following the

orders as prescribed by the ancestors (Labuschagne et al., 2003:108). Ngong (2000:28) adds that indeed failure to appease ancestors or follow their orders results in severe punishment from these ancestors.

Within the context of the study, the parents as caregivers of adult children living with schizophrenia can be motivated by their beliefs to take action against the perceived threat of schizophrenia. The more severe the schizophrenia is perceived to be, the higher the possibility of parents as caregivers taking action to manage and control the disease. The parents as caregivers presumably evaluate the level of punishment that can be experienced by the family if they do not follow the instructions as set out by ancestors. This will result in consultations with traditional healers and sangomas who will assist the families to perform specific rituals set out to appease ancestors. This type of action is beneficial as it is motivated by the possibility of avoiding punishment from ancestors which can take the form of more severe diseases which are incurable.

- **Perceived barriers to taking action**

Perceived barriers to taking action explain the negatively valued aspects of action to be taken. This step is very significant in deciding to take action as the perceived barriers will determine whether change will occur or not (Jones & Bartlett, 2004:26). Barriers to taking action include, but are not limited to, fear of change or learning a new habit, anticipated difficulty in learning a new behaviour, and fear of the outcomes of a behaviour such as pain, embarrassment, and social exclusion (Lizewski, 2010:460).

Fear of change is notably a challenge for many people. People get accustomed to specific ways of life and when situations arise where change is probable, the feelings of fear are evidently observed. The researcher argues that parents as caregivers of adult children living with schizophrenia can notably experience feelings of fear and anxiety, as known life circumstances would change in a drastic way. Fear of social exclusion from the community and stigma towards the

family might arise in cases where the family has to publicise their adult children's mental illness through attending community psycho-educational programmes. The evaluation of the impact of the result of the new behaviours to be adopted will determine whether the family will take the risk of adopting the new behaviour or not. The adoption of the new behaviour will only be considered if the perceived positive outcomes outweigh the perceived negative outcomes.

- **Cues to taking action**

Cues to action are identified by Brieger (2006:52) as events, people or things that persuade people to change their behaviour. The magnitude of the cues to take action motivates the degree of probability of the action being taken (Jones & Bartlett, 2004:24). Taylor et al. (2007:22) add that cues to take action might take the form of advice from relatives, friends, community members, the media, or health care professionals; seeing someone else suffering from a specific disease; and having lost a significant other to a specific disease. Within the context of the study, the parents as caregivers of adult children living with schizophrenia can be motivated to take action regarding their adult children's schizophrenia mainly because of their personal experience with the impact of schizophrenia on their lives. The schizophrenia affecting their adult children is enough motivation for them to seek adequate knowledge and information followed by positive actions to manage and control the disease.

- **Motivating factors**

The identified modifying factors of perception about a condition include, amongst others culture, educational level, motivation, skill, and past experiences. Perception of a condition is most often evaluated primarily by past experiences and personal cultural beliefs (Brieger, 2006:52). The past experiences of a condition within a family setting will determine the level of susceptibility and seriousness within that specific family. Belief systems used to explain the condition will then determine the course of action and outcomes, usually still focusing on past experience and results (Taylor et al., 2007:26). As stated earlier,

African cultural beliefs and past experiences within such families determine the perception of the disease.

Parents as caregivers of adult children living with schizophrenia would recall all experiences of family members or community members who suffered from schizophrenia and what results were produced by actions or decisions taken by them. If the results were positive, possibly the same response or action might be considered. If the results were negative, alternative actions might be considered in pursuit of positive outcomes. The notion of spirit reincarnation motivates the belief and perception of susceptibility within these families. Parents as caregivers of adult children living with schizophrenia therefore consider cultural explanations and past experiences with schizophrenia which in turn determines the course of action to be taken, which in this case would probably be consultation with traditional healers (Curationis, 2002:223).

- **Self-efficacy**

Rabkin and Ramien (2001:212) describe self-efficacy as the confidence in one's ability to perform a health behaviour. Brieger (2006:54) expands further that people generally try new things when they believe that they can perform such things. The researcher argues that after the process of evaluating perceived susceptibility to and seriousness of an illness, as well as the benefits of taking action and barriers to taking action, parents as caregivers of adult children living with schizophrenia can then make a choice to take action as long as they believe in their capability to perform such tasks. An example could be parents as caregivers deciding on attending psycho-educational programmes during weekends to learn more about schizophrenia and how to manage the disorder. This will make their caregiving responsibilities much easier as they would know what to expect in performing this task.

The Health Belief Model has proved to be an effective model in predicting health behaviour and motivating positive health behaviour change. It is worthy to note that the

Health Belief Model is not only useful in explaining and predicting health-related behaviour, but has more positive contributions to health which are discussed below:

- Firstly, the Health Belief Model is a meta-systematic theory that is effective in predicting and effecting health behaviour change. Its meta-systematic nature allows for use of the model not just in one health condition, but all health conditions (Jones & Bartlett, 2004:12).
- Secondly, the model's perceived barriers as predictors of subsequent behaviours promote a clear scope of modifying variables to be considered as influencing non-compliance in health behaviour. Because there can never be a general quantifiable measure of variables, more barriers can be identified and recognised as influencing non-compliance (Brieger, 2006:48).
- Thirdly, the component of self-efficacy provides an exploration of the extent of individual capabilities in undertaking new health behaviours. The decision to take action or not will probably determine the level of self-efficacy from the person's point of view because, as noted earlier by Brieger (2006:48), people generally try something new only if they are confident that they can perform the behaviour.
- Fourthly, the Health Belief Model has a positive impact on health outcomes. Predictions of health-related behaviours assist health care professionals and programme developers to develop target oriented programmes in terms of outcome-based results (Lizewski, 2010:454). It further promotes improved health services as its predictive nature provides for possible reasons for non-compliance (Taylor et al., 2007:22).
- Finally, the model's effective prediction of possible reasons for non-compliance expands further to promotion of effective and accurate recommendations for further actions in response to health behaviour challenges.

In conclusion, the Health Belief Model predicts preventative health behaviours and behavioural responses. It attempts to predict health-related behaviour in terms of certain personal belief patterns. Three distinct factors are promulgated within the model, namely: individual likelihood of action perceptions, which include perceptions about illnesses; modifying factors, which include demographic variables or cues; and likelihood of action, which include factors in probability of appropriate health behaviour (Jones & Bartlett, 2004:16). Explanations of health-related behaviours are highly influenced by personal values, norms and standards that shape individual reality. It is therefore arguable that explanations of disease vary from one cultural setting to another. The use of modifying variables also promotes a sense of explanatory value to decisions made by individuals in terms of health-related behaviours. The model emphasises consideration of personal cultural belief systems in dealing with health-related behaviours, as such belief systems shape personal realities. The explanatory value of health-related behaviours as linked to culture promotes opportunities for cultural sensitivity to health care professionals. Put in simple terms, this means that no health-related behaviour can be adequately understood or explained without first considering the cultural background of the specified population.

Because the profession of social work strives for health promotion and human empowerment, primarily on primary prevention, the Health Belief Model's preventative nature blends well within the scope of the work in ensuring that the objectives of health promotion and empowerment are achieved. This is achieved through the model's ability to encourage individuals to take responsibility for their own health through their perception of the risk of specific diseases. The model provided a concise exploration of the cultural belief systems as held by parents as caregiver of adult children living with schizophrenia throughout the study.

1.3 RATIONALE AND PROBLEM STATEMENT

Culture plays an important role in people's lives, as it shapes society. Matthews (2010:02) defines culture as a set of shared norms, standards and expectations by a

specific group of individuals. Africans have their own cultural beliefs that shape their day-to-day lives. Culture is influential in the decision-making process and the way Africans perceive specific life experiences. Health challenges are among the aspects considered to be communication from ancestors in African contexts (Curationis, 2002:222). This then results in action taking where Africans consult traditional healers to seek a clear understanding of the ancestors' communication.

There are different explanations of health problems in the African context itself (Makau, 2003:10), thus the aim of the study was to explore the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community. The interest in the conducted study was motivated by the notion that African culture is not clearly understood in relation to schizophrenia. Schizophrenia carries many symptoms which, in an African context, are not necessarily attributed to a just a plain disease, but vital communication from ancestors. The researcher deemed the conducted study necessary as with the aim of showing the lack of knowledge about schizophrenia by parents as caregivers of adult children living with schizophrenia. Furthermore, the study was conducted to show that Africans are influenced by cultural beliefs in terms of explaining disease, specifically schizophrenia. The study thereby fills the gap of inadequate knowledge with regards to schizophrenia in relation to cultural beliefs through the provision of understanding the cultural context of Africans when explaining diseases such as schizophrenia.

Most of the research studies conducted by authors such as Makau (2003:33) and Curationis (2002:223) focus on African culture with Western influenced explanations. The studies on African culture focus more on treatment options than the reason for opting for such treatments or the perception of disease itself. The gap in these studies is that the belief that mental illness is caused by witchcraft or communication by ancestors is explored by few researchers. The lack of researched knowledge, facts and awareness about the different causes of mental illness in African cultures is inadequate. This increases the likelihood that Africans will seek traditional assistance in terms of managing mental illness, as it is the only option they are knowledgeable about.

The holistic context of culture in relation to mental illness is not explored, especially schizophrenia. This illness is highly prevalent in African communities and largely thought of as caused by witchcraft, yet such cultural aspects have not been adequately explored (Makau, 2003:42). The dearth of research on African culture in relation to mental illness, specifically schizophrenia, also serves no justice to the academic and health spheres in knowledge about cultural connotations of mental illness. The lack of cultural sensitivity therefore means poor social justice to culturally influenced populations which is in contradiction to the values and principles of the social work profession, hence it was crucial for the conducted study to explore the phenomenon of cultural beliefs of caregivers of adult children living with schizophrenia in a rural African community in pursuit of adding value to the awareness of cultural sensitivity and culturally influenced health explanations for other professionals.

The overlap between the symptoms of schizophrenia in Western culture and those of communication from the ancestors in an African context makes it imperative to make a distinction between the two. A distinction can only be made through a thorough study of African culture in relation to schizophrenia. The best way to achieve this goal is by engaging with people experiencing this phenomenon; thus the study explored the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community. The parents as caregivers of adult children living with schizophrenia were the target population, as they have first-hand experience of what the study was exploring. It is thus for this reason that the researcher was of the opinion that there was indeed a vast gap in the explanation of cultural beliefs as perceived by parents as caregivers in terms of schizophrenia in a rural African community.

Understanding the phenomenon of mental illness is central to the conducted study, focusing on the main tenets of cultural beliefs in relation to schizophrenia. The conducted study might contribute positively to the field of social work by providing social workers and other health care professionals with knowledge about and insight into the belief systems that are valued by Africans in rural areas. This might foster improved

assessment processes by the social professions, because of the centralised nature of focusing on a holistic approach (Nilsson, 2003:46), taking cultural beliefs into consideration. The improvement of services might enhance cooperation from clients.

As mentioned earlier, most health professionals were reported to lack cultural awareness and sensitivity in relation to health (Breen et al., 2009:327), thus the study was conducted with the hope to empower social work professionals and other health care professionals with an understanding of their clients' culture, cultural beliefs, and reasons for certain treatments in terms of health problems. The conducted study was inspired by the positive contribution in the achievement and fulfilment of social work values, such as social justice and access to resources, as it highlighted the systems that mental health care users and their families can be equipped with to promote their wellbeing. Furthermore, the conducted study was motivated to promote fair treatment of mental health care users by promoting an understanding of schizophrenia, reducing stigma in communities, and empowering the caregiver experience by strengthening cooperation with other systems.

In conclusion, it is of highest importance for mental health care users and their families to be knowledgeable about the Health Belief Model and its constructs as it is prevention-focus oriented. The Health Belief Model will therefore invariably motivate mental health care users and their families to take responsibility for their own health wellbeing by fostering an investment in their own personal health. The model will further motivate mental health care users, families and communities to be aware of their own personal cultural beliefs in relation to health-related behaviours. The model will sensitise health care professionals to cultural belief systems in relation to health-related behaviours. The model will further assist them to mobilise communities through group, community, and self-help educational programmes and to plan and implement effective health-related behavioural programmes.

The research study was guided by the following research question “***What are the cultural beliefs of parents as caregivers of adult children living with schizophrenia?***”

1.4 THE GOAL AND OBJECTIVES OF THE STUDY

The research goal and objectives of the study are discussed below.

1.4.1 Research goal

The goal of the study was to explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community.

1.4.2 Research objectives

- To conceptualise mental illness in relation to cultural beliefs in rural African communities.
- To explore the cultural beliefs of parents as caregivers of adult children living with schizophrenia.
- To explore the needs and challenges of parents as caregivers of adult children living with schizophrenia.
- To make recommendations for the improvement of social work services provided to parents who are caregivers of adult children living with schizophrenia.

1.5 RESEARCH DESIGN AND METHODOLOGY

This section is a brief summary of the research methodology that was utilised throughout the study. The detailed research methodologies, which include research approach, research type, research design, research methods, ethical considerations, and trustworthiness of data, will be discussed and presented in Chapter Three.

This study is qualitative in nature as it aimed to elicit the cultural beliefs of parents as caregivers of adult children living with schizophrenia from their own personal accounts (De Vos, Strydom, Fouché & Delport, 2011:74). The qualitative nature of the study allowed the researcher an opportunity to gain in-depth understanding of the cultural beliefs of parents as caregivers of adult children living with schizophrenia in rural African communities. The exploratory nature of the study further assisted the researcher to elicit personal meanings attached to schizophrenia in the context of cultural beliefs as experienced by parents as caregivers of adult children living with schizophrenia.

The type of the research study was applied research which allowed the researcher an opportunity to explore and gain answers to the phenomenon of schizophrenia (Babbie, 2007:25) as perceived by parents as caregivers of adult children living with schizophrenia in a rural African community. A collective case study design was utilised to gain an understanding of the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community. The choice of a collective case study was motivated by its exploratory nature which allows for the collection of rich data, directly from the participants (Rubin & Babbie, 2011:442).

The research population was formed by parents who are caregivers of adult children living with schizophrenia, attending Mfihlakalo Day Care Centre in a rural African community called Klipgat, in the North West Province, South Africa. The community is diverse in nature with inhabitants hailing from different cultural backgrounds. The total population of the community is made up by black Africans. There are inadequate mental health service centres within the community as community members depend on one local clinic for primary mental health services. Majority of the community members are traditional in nature and believe in ancestors and traditional medicine. Mental illness in the area is predominantly perceived as caused by witchcraft or ancestral influences. A non-probability, purposive sampling technique was utilised to explore elements that characterised the most appropriate attributes relevant for the purpose of the study (Strydom, 2005a:302). The data was collected through the use of semi-structured, one-to-one interviews which allowed the researcher an opportunity to gain a detailed

understanding of parents' perceptions as caregivers with regard to schizophrenia (Greef, 2011:351). Furthermore, the interview allowed the researcher flexibility in questioning the participants with the guidance of an interview schedule. The use of an interview schedule assisted in organising questions and guiding the flow of the interview (Greef, 2011:353).

The research methodology assisted the researcher to follow a logical and methodological process of data collection in pursuit of meeting the goal and objectives of the study. As indicated earlier, further details with regard to the methodologies utilised throughout the study will be thoroughly discussed and presented in Chapter Three.

1.6 LIMITATIONS OF THE STUDY

It is worth noting that the study has successfully reached its aims, although there were inevitable limitations to the study. Firstly, the recruitment process of the study was in a quandary due to the fact that the diagnoses of most of the adult children in the day care centre were not properly understood. This caused a rift as the study was aimed at exploring schizophrenia. The day care centre principal had to go through all the case files to ensure that the proper recruitment process was undertaken. Secondly, the participants' level of dissatisfaction towards lack of service delivery to mental health care users might have influenced their responses within the study, subsequently influencing the findings, conclusions and recommendations of the study. However, the researcher was careful to reflect the participants' responses. Thirdly, the participants' level of education was a challenge as most of the participants could not contextualise the phenomenon of schizophrenia. For this reason it was challenging to draw general conclusions for the study. There is an evident need for further studies in this regard, along with psycho-educational programmes. Finally, the dearth of research studies on cultural beliefs and mental illness made it challenging to collect literature. The available literature was either very old (10 years or older) or irrelevant to the conducted study. There is definitely a greater need for further studies on the subject matter.

1.7 CONTENT OF THE RESEARCH REPORT

The research report is delineated into four chapters which are structured as follows:

- **Chapter One** outlines the introduction and general orientation of the study. A comprehensive introduction of the research topic is deliberated on, along with a broad spectrum of definition of key terms. Further components discussed within this chapter include the theoretical framework, rationale and problem statement, goal and objectives of the study, a brief overview of the research methodology, and the limitations of the research study.
- **Chapter Two** outlines the phenomenon of cultural beliefs in relation to schizophrenia. The chapter comprehensively discusses the in-depth debates and arguments on the cultural beliefs and schizophrenia from a Health Belief Model point of view. The discussions include the link between cultural beliefs and parental caregiving, and cultural beliefs and mental illness as experienced in a rural African context.
- **Chapter Three** is an in-depth discussion of the research methodology as utilised throughout the study. A comprehensive discussion of the research approach, type of research, research design, study population, sampling, data collection, data analysis, pilot study, and ethical issues is included. The presentation and discussion of the research findings are also incorporated in this chapter.
- **Chapter Four** is the final chapter of the research report and includes the conclusions and recommendations of the research study. In this chapter, the researcher reflects on how the goal and objectives of the study were achieved. The key findings of the study are also highlighted in this chapter along with detailed recommendations drawn from the key findings of the study.

The next chapter is centred around the detailed discussion on schizophrenia and culture.

CHAPTER TWO – SCHIZOPHRENIA AND CULTURE: A LITERATURE REVIEW

2.1 INTRODUCTION

This chapter is a review of the literature sources consulted about the research topic. Fouché, Delpont and Schurink (2011:298) indicate that a literature review is important in that it allows the reader to grasp the facts of the proposed study and helps researchers to discover new fields and open new understandings. The review of literature provides an array of factual information from various sources about the cultural beliefs of parents as caregivers of adult children living with schizophrenia in the rural areas. This chapter contextualises schizophrenia and culture from perspectives of diverse authors who produced material on the subject matter.

2.2 HISTORICAL BACKGROUND OF MENTAL ILLNESS

Pilgrim (2009:80) asserts that the Lunacy Act in 1890 required that all people entering asylums be detained compulsorily and certified of insanity. It was only in 1930 that the Mental Treatment Act introduced the notion of community care and allowed voluntary admissions. Asylums were abolished after the Second World War. The final formalities of asylum abolishment took place in 1980, when only 8% of the overall admissions were involuntary (Pilgrim, 2009:80).

Nationally, after democracy in 1994, the South African Health System took a radical turn with the reconstruction of the health system giving birth to new policies such as mental health care act and the White Paper for the transformation of Health Systems in South Africa. The Health Care System was reorganised with the patronage and advocacy of the WHO. The White Paper for the Transformation of the Health System in South Africa (RSA, 1997b) promoted a comprehensive Health Care System, the Primary Health Care System, as advocated by the WHO's Alma Ata Declaration of 1978. The basic tenet of Primary Health Care System was to understand illness through an approach that

integrates the biological, social, cultural, and psychological aspects of individuals to understand their ailments in a holistic framework (Pilgrim, 2009:24). At this time, mental health services were run parallel to other health services. The reconstruction of health systems and birth of mental health policies played a major role in advocacy for mental health care users which resulted in implementation of resources for mental health care users. Mental health care users started the enjoyment of benefits such as specialised schools, social support grants and access to medical treatments through the new health system. The process of deinstitutionalisation of mental health care services was then implemented, whereby mental health care users were moved from asylums and placed with their families. This resulted in families becoming the primary informal caregivers responsible for the wellbeing of individuals living with a mental illness, with health professionals playing a secondary role (Pilgrim, 2009:24). The conducted study explored caregiver's opinions and perceptions with regards to mental illness in relation to cultural beliefs. The formulated policies such as the White Paper for transformation of Health Systems in South Africa along with the Mental Health Care Act have laid a foundation whereby mental health care users and their caregiver's opinions are placed as a cornerstone to identify the gaps within the mental health field through consultation and advocacy. The researcher identified an opportunity whereby she consulted with the caregivers of mental health care users to contribute to the promotion of mental health care services through the results of the study.

It has been argued by some professionals that removing a health care user from the social context in which their mental crisis occurred and then returning them back to the same context is not in any way helpful (Pilgrim, 2009:81). Pilgrim (2009:81) further notes that using hospitals as institutions for recovery was not effective in that problems cannot be rectified in an isolated setting. Pilgrim (2009:82) argues that hospitalisation only provides temporary assistance, as the patient has to go back to society after all. For this reason Pilgrim (2009:82) suggests the move for crisis intervention in communities rather than hospitalisation.

The term schizophrenia was coined in 1908 by a Swiss Psychiatrist, Eugen Bleuler. The word was derived from the Greek words “schizo”, which means split, and “phren”, which means mind. In totality it means a split mind (Townsend, 2005:272). In the 1800s a Belgian physician, Benedict Morel, derived the term *démence précoce* which means early mental deterioration. This was derived after Morel observed the symptoms of a 13 year old boy whose functioning had declined over a period of time. In the 19th century a German psychiatrist, Emil Kraepelin, adjusted the term to *dementia praecox*, distinguishing the cognitive aspects (dementia) and age of onset (praecox), along with the course of the disorder which involved deterioration over a period of time (Burke, 2012:197).

Kraepelin further contributed to the ideation of various manifestations of dementia praecox, which were regarded as distinctive disorders themselves. These conditions were catatonia (immobility or agitation), hebephrenia (apparent immaturity), and paranoia (persecutory or grandiose delusions). He identified the distinguishing features of the condition as hallucinations, delusions, and a decline in cognitive functioning as symptoms of the disorder (Burke, 2012:198). However, Bleuler seems to be in disagreement with Kraepelin as he believed that schizophrenia was not only marked by a course of deterioration. His split mind explanation suggested a split between intellect, emotion, behaviour and external reality, rather than multiple personalities (Burke, 2012:198). He further alluded to the symptoms of the condition as affecting the four A's: autism (self-focus), associations (loose or unconnected ideas), ambivalence (lack of resolve over actions), and affective disturbances (emotional inappropriateness). Unlike Kraepelin, Bleuler regarded hallucinations and delusions as secondary symptoms of the disturbance (Burke, 2012:198).

Townsend (2005:272) asserts that schizophrenia is a heterogeneous disorder with variable combinations of biochemical dysfunction, physiological factors, genetic predisposition and psychosocial stress. There is also no single cure or form of treatment to manage and treat schizophrenia. Videbeck (2009:267) is in consensus with Townsend and adds that schizophrenia is a syndrome of disease processes or

experiences with different manifestations and symptoms. This results in misunderstandings about the disease due to the variety of presenting symptoms.

It is thus arguable that schizophrenia is a complex disorder with varying symptoms. There are many authors and theorists that have contributed to the founding of the term schizophrenia and the explanation of the disorder is still evolving. The researcher is of the opinion that further explorative studies on the disorder will promote an in-depth understanding of the disorder for health professionals to aid better diagnosis, treatment and management of the disorder. For families and communities it will aid an understanding and awareness of the disorder, the dynamics in caring responsibilities, accessing resources and how to better deal with the challenges it bears.

2.3 GAP IN MENTAL HEALTH STUDIES

Africans perceive mental illness to be linked to cultural beliefs, such as punishment for failure to adhere to ancestral laws, possession by evil spirits, and witchcraft (Mosotho, Louw, Calitz & Esterhuize, 2008:160). Only 2% of the research in South Africa is dedicated to mental health (South African Depression and Anxiety Group, 2010), thus the researcher is of the opinion that the fact that there is minimal research conducted on this phenomenon explains the gap in information on the cultural beliefs regarding mental illness and culture, specifically schizophrenia, in rural African communities.

There is a paucity of studies on accounts of patients or their caregivers regarding their personal, first-hand experiences of mental illness. Pilgrim (2009:67) asserts that researchers focus their attention on health rather than illness itself. He further asserts that researchers show very little interest in the personal accounts of their patients. This shows the gap in information regarding mental health care users' account of illnesses. Pilgrim (2009:68) further adds that even when researchers focus their attention on patients or their caregivers, they dismiss patients' account as lacking logic. Patients themselves are not trusted to provide credible information due to their mental incapacity.

Families as caregivers are viewed as major role players in the treatment and management of people living schizophrenia. It is therefore the researcher's opinion that it is of great importance to consider the caregivers' opinions regarding caring for people living with schizophrenia. Caring responsibilities are usually the responsibility of direct parents, especially mothers or female relatives, and siblings. Except for the caring responsibilities, caregivers play a crucial part during diagnosis and consultations of those living with mental illnesses, as they can give an account of the presenting symptoms as directly observed (Ivey et al., 2012:809).

Anderson and Adams (1996:505) reiterate on the systematic review studies conducted by Mari and Streiner on family interventions, which emphasise that the supportive role of families as caregivers is of high importance in caring for people living with schizophrenia. These roles were linked to reduced relapse rates and re-hospitalisation, and an increase in compliance with medication, as compared to those living in families characterised by high levels of hostility, criticism and emotional over-involvement. Family intervention strategies were most effective because they also offered family psycho-education and support, and included some form of skills-based training for relatives, although the theoretical orientation of these programmes varied considerably with reference to cultural backgrounds of the families.

Although parents as caregivers play a major role in the treatment and management of their family members living with schizophrenia, bias in interpretation of symptoms by caregivers cannot be overlooked. Asmal, Mall, Kritzinger, Chiliza, Emsley and Swartz (2011:368) indicate that parents as caregivers usually give a history containing many apparent contradictions. These contradictions are motivated by the level of suffering from some of the caregivers as they believe that exaggeration of the symptoms might motivate health care professionals to move dependants to a more controlled environment, in turn relieving them of the caring responsibilities. The need for psycho-education and support strategies, as mentioned earlier by Mari and Streiner, in family

intervention strategies prove to be an effective process to families of people living with schizophrenia.

2.4 SCHIZOPHRENIA

The American Psychiatric Association (APA) (2015) proclaims that schizophrenia is characterised by diagnostic symptoms ranging between cognitive, behavioural and emotional dysfunction or abnormalities. These abnormalities include delusions, hallucinations, disorganised speech, grossly disorganised or abnormal motor behaviour, and negative symptoms. There is no single symptom that is pathognomonic of the disorder. Those diagnosed with the disorder present with varying features, as the disorder is a heterogeneous clinical syndrome.

The APA (2015) refers to schizophrenia as a severe type of mental illness constituting a disturbance that lasts for at least six months, of which one month is an active phase of symptoms such as hallucinations and delusions. Schizophrenia is also explained as a disorder characterised by a broad spectrum of cognitive and emotional dysfunctions, including delusions, hallucinations, disorganised speech and inappropriate emotions (Barlow & Durand, 2009:467). People living with schizophrenia are detached from reality. The symptoms are severe and episodic in nature.

2.4.1 Diagnosis

There are a lot of factors to be taken into consideration when making a diagnosis of schizophrenia. Such factors include the recognition of signs and symptoms associated with impaired occupational or social functioning (APA, 2013). Clinicians need to be aware of and sensitive to cultural and socioeconomic factors of individuals in order to make an accurate diagnosis (APA, 2013):

There should be at least two Criterion A symptoms, present for a significant portion of time during a one month period or longer. At least one of these symptoms must be a clear presence of delusions, hallucinations or disorganised speech.

The diagnostic criteria for schizophrenia according to the APA (2013) are as follows:

- A. Two or more of the following, each present for a significant portion of time during a 1 month period (or less if successfully treated). At least one of these must be (1), (2) or (3);
 1. Delusions
 2. Hallucinations
 3. Disorganised speech (e.g., frequent derailment or incoherence)
 4. Grossly disorganised or catatonic behaviour
 5. Negative symptoms (e.g., diminished emotional expression or avolition)
- B. For a significant portion of the time since the onset of the disturbance, level of functioning in or more major areas; such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, there is failure to achieve expected level of interpersonal, academic or occupational functioning).
- C. Continuous signs of the disturbance persist for at least 6 months. This 6 month period must include at least one month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or by two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. Schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either 1) no major depressive or manic episodes have occurred concurrently with the active-phase symptoms, 2) if mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.
- E. The disturbance is not attributed to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.
- F. If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least one month (or less if successfully treated).

2.4.2 Statistics and prevalence of schizophrenia

Burke (2012:198) argues that schizophrenia affects 0.5% - 1.5% of the adult population worldwide, while the APA (2013) declares that the lifetime prevalence appears to be

approximately 0.3% - 0.7% with varying differences in terms of race or ethnicity. Van Wyk (2014) states that schizophrenia affects one in three people. The article further adds that 15% of people living with schizophrenia are hospitalised.

The APA (2013) specifies that the age of onset is between the late adolescent stage and early 30s. An earlier age of onset denotes a predictor of a later worse prognosis. Onset prior to adolescence is rare. It is also difficult to diagnose schizophrenia in childhood although there are evident symptoms (APA, 2013). The peak onset for the first psychotic episode is in the early 20s to mid-20s for males, and late 20s for females.

The gender ratios of schizophrenia differ across populations. Males have been reported to present with more negative symptoms, prominent cognitive impairment, and longer duration than females. This has been explained by theorists as related to gender stereotypes such as the belief that males have a worse premorbid adjustment and lower educational achievement which influence the emergence of the disorder. In other settings, females present with more symptoms. This has been explained by theorists as pertaining to factors contributing to the emergence of the disorder such as hormones and vulnerability to stress (APA, 2013).

From the overall number of the people living with schizophrenia that are on treatment and adhering to it, 10% are living with their families. Families of origin are the main caregivers for people living with schizophrenia, which affects family functioning as the family has to adjust to the illness and underlying caring responsibilities (Public Health, 2013). The researcher strongly believes that the prevalence of schizophrenia sends out a message that the illness needs to be studied in-depth in order to understand how it affects individuals along with their families across all cultures. The researcher is therefore interested in African culture, as adequate studies are not being undertaken in this racial sphere.

The researcher is of the opinion that schizophrenia as a form of mental illness poses challenges to the emotional, physical and economical functioning of the individual

experiencing it. Caregivers experience emotional stress and physical strain while caring for their family members diagnosed with schizophrenia. It is for this reason that the researcher deems the proposed study of great relevance, as it seeks to explore the experiences of caregivers of adult children living with schizophrenia, taking into consideration the cultural beliefs attached to it. The researcher thus explores schizophrenia further to seek an understanding of the illness itself.

2.4.3 Aetiology

There are no known proven causes of schizophrenia. Currently researchers and health care practitioners resort to genetic, social and environmental factors as playing a role in the manifestation of schizophrenia (APA, 2013). The contributing factors are discussed below.

2.4.3.1 Biological Causes

Genetic factors

Genes have been identified as a contributing factor to the aetiology of schizophrenia. There is evidence indicating that instead of a single gene, there are multiple genes linked to the aetiology of schizophrenia. These genes give rise to an inherited vulnerability to developing the disorder. It is argued that vulnerability to schizophrenia by individuals with shared genetics with family members who live with schizophrenia is evident. Jong (2003:33) asserts that Africans believe in reincarnation of the spirit of deceased family members. These spirits find new life in another family member who is alive. This transference of spirits only occurs within direct family members, meaning that immediate family members have a high likelihood to receive the gift from their ancestors. According to the researchers' opinion, this means that the transference of spirits occurs within a specific family blood line, indicating the role of genes in that regard. Genetic inheritance can also be predisposed and explained by the following:

- **Twin studies**

Although the concordance rate to develop schizophrenia for monozygotic (identical) twins should be 100% as they share 100% of their genetic material (Burke, 2012:220), twin studies argue that monozygotic twins only have a 50% risk for developing schizophrenia if the other twin has the disorder (Videbeck, 2009:272). People with close relatives living with schizophrenia are more than likely to suffer from the disease (Kaplan, 2002:454). This is most likely to occur among those with both parents living with schizophrenia. In an African context, the same explanation by Jong (2003:33) applies that only families whose ancestors had the gift stand a chance of getting the transference of the spirit.

- **Brain structure**

Brain abnormality has been suspected to be a causal factor for the development of schizophrenia, putting much focus on enlarged ventricles and decreased activity in the frontal lobes (Burke, 2012:221). Large ventricles have been found to be associated with poor pre-morbid adjustment, while decreased activity in frontal lobes are associated with dysfunction in areas of thinking, reasoning and social behaviour. People living with schizophrenia normally show abnormalities in their brain structure which is captured through a variety of scans such as CAT scans (Burke, 2012:221). This evidence shows that there is a link between schizophrenia and abnormal brain structure, along with other causal factors.

- **Biochemical factors**

Since the founding of the term schizophrenia, many theorists have been focusing on chemical disturbance as an explanation for the disorder. The pathogenic role to abnormal brain biochemistry has assisted theorist and health care workers with explanations of the disorder (Burke, 2012:222). The theorists focused on neurotransmitters, including dopamine, serotonin and norepinephrine. Videbeck (2009), Townsend (2005) and Burke (2012) are in consensus that the dopamine hypothesis has taken centre stage in terms of explaining the link to

schizophrenia. It is argued that schizophrenia is linked to an excess of dopamine neuronal activity in the brain. Pharmacological support for this hypothesis has proven that excess dopamine plays a role in schizophrenia. Africans also believe in biochemical factors and it is asserted that an excess of gall bladder and phlegm also causes implications in the body. This is resolved by a process called “*ukuphalaza*” which means purging with specific herbs prescribed by a traditional healer (Ellis, 2004:36).

2.4.3.2 Physiological influences

There are possible physical influences that have been linked to schizophrenia, although the implications are unclear. Viral infections have been reported to show a strong link to schizophrenia. This link has been observed after prenatal exposure to influenza. Birth complications have also been noted although the studies were inconsistent (Videbeck, 2009:42). Ellis (2004:30) indicates that Africans also have a belief about foreign substances being put in a human’s body through witchcraft practices. This may be done through putting poison in food or drinks, making the victim step on strong medication, or eating in dreams. This is called “*isidliso*” and needs the powers and herbs of a traditional healer to remove them from the individual’s body (Ellis, 2004:30).

2.4.3.3 Psychological causes

- **Stressful life events**

The presence of stress preceding the onset of schizophrenia is often from stressful events in an individual’s life, such as difficulties in close personal relationships or previous traumatic experiences (Burke, 2012:225).

- **Faulty learning**

Faulty learning manifests in assumptions about reality, emotional immaturity, difficulties regarding self-worth and lack of coping skills. It may further be related to exposure to early traumatic experiences, such as disruptions in parenting,

observing role models behaving in grossly inappropriate ways, and disturbed social interactions (Burke, 2012:225).

2.4.3.4 Expressed emotion

Expressed emotion is explained as a pattern of communication which is characterised by statements expressing criticism, hostility and over-involvement. Expressed emotion is not regarded as a primary causal factor for schizophrenia, but as a precipitating factor that influences or exacerbates the symptoms of the disorder (Burke, 2012:228).

2.4.3.5 Environmental factors

- **Social factors**

The National Institutes of Health (NIH, 2001) indicates that a poor social life contributes to the development of schizophrenia, because such individuals do not have adequate emotional support. Most people living with schizophrenia have fewer friends or social interactions. They keep to themselves and do not relate well with others. The emergence of mental illness within a family with African cultural beliefs characteristically brings shame and often serves to isolate the individual and family (McInnis & Merajver, 2011:168).

- **Socioeconomic factors**

Many of the people living with schizophrenia are from low socioeconomic classes highly impacted by poverty. These individuals are stricken by malnutrition, inadequate prenatal care, lack of housing or congested housing conditions, and lack of proper health care services. These factors have been linked to symptoms of schizophrenia, although the studies are inconsistent (Townsend, 2005:274). The researcher is in support of this statement, because most Africans are still living in poor socio-economic circumstances. The area where the proposed study is to be conducted is itself a village that is prone to a lack of resources, high unemployment rates, and low cost housing.

2.4.3.6 Cultural factors

According to Labuschagne et al. (2003:109), cultural beliefs shape social interactions thus leading to specific perceptions about different aspects. Videbeck (2009:272) asserts that cultural explanations of diseases play a major role in explaining how people perceive schizophrenia. Different cultures hold different beliefs to explain specific life events, thus what is perceived as abnormal in one cultural setting might be normal in another. For example, ideas considered delusional in one country, such as witchcraft and sorcery, might be accepted in another.

Ngong (2000:48) indicates that the ancestors send messages to the chosen individual through visions or dreams, or by talking to them. This is called a calling and it can only be transferred from an ancestor who had the gift. This notion is relevant as vulnerability plays a role, since the family has a history of such gifts. This means that most often the calling comes from an ancestor who had the gift, transferring it from generation to generation. As indicated earlier by Labuschagne et al. (2003:109), cultural beliefs shape social interactions thus leading to specific perceptions about different aspects. In this instance, Africans believe mental illness to be caused by witchcraft, spirit possession or communication by ancestors.

The researcher argues that the social construction of culture plays a major role in the perception of mental illness, specifically schizophrenia. Although there are evident heterogeneous causal factors for schizophrenia, cultural connotations seem to stand out as one of the factors. Populations that embrace their culture select specific ways to explain schizophrenia, guided by their cultural values. In the context of this study, the in-depth understanding of the African population with regard to schizophrenia will provide evidence on how the disease manifests in their specific setting.

2.4.4 Symptoms

2.4.4.1 Positive symptoms

The positive symptoms of schizophrenia include delusions, hallucinations, disorganised speech, and disorganised or catatonic behaviour. Delusions are described as

misinterpretations of reality, also known as the basic characteristic of madness. Hallucinations are sensory events without any input from the surrounding environment. Hallucinations present themselves in the form of visions or objects unseen by others (Barlow & Durand, 2009:467). Disorganised speech is explained by Burke (2012:206) as a verbal communication that does not conform to linguistic rules. This means the person's communication is illogical as they move from one point to the other. This form of symptom can take various forms such as: 1) loosening of associations whereby the individual moves between unrelated ideas during a conversation; 2) problems with attention which involves inability to direct sustained attention; and 3) speech disturbances whereby the individual uses new words that cannot be understood (Burke, 2012:207).

2.4.4.2 Negative symptoms

The negative symptoms of schizophrenia include flat affect, avolition and alogia. It is described as erratic behaviours that affect speech, motor behaviour, and emotional reactions (Barlow & Durand, 2009:473). Disorganised speech often presents itself in the form of babbling, illogical speech, or flat affect. Labuschagne et al. (2003:108) indicate that when individuals are contacted by ancestors, they talk to themselves in a language unknown to others, often perceived as babbling. Makau (2003:12) adds that unusual facial expressions are evident during such communication with ancestors. The researcher is of the opinion that the symptoms correlate both in African culture and in Western contexts.

The researcher asserts that the symptoms of schizophrenia could rather be perceived in a negative way in an African context, as they correlate with symptoms experienced by people who are thought to be possessed. The symptoms could then again be perceived in positive light as a crucial means of communication from the ancestors. Africans construct their social experiences through cultural beliefs. They believe that ancestors speak to them through dreams, voices or visions which others cannot see or hear (Makau, 2003:09). This shows the link between schizophrenia and culturally defined mental health challenges in African communities due to shared symptoms.

2.4.5 Classification of schizophrenia

The classification of schizophrenia has evolved with the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) having excluded the previously used classifications of subtypes for the disorder. 'Schizophrenia spectrum and other psychotic disorders, including personality disorders' is the accredited classification of schizophrenia as used in the DSM 5. The sub-types of schizophrenia are no longer applicable in terms of diagnosis. The psychotic and personality disorders recognised as linked to schizophrenia include schizotypal, brief psychotic, and schizophreniform disorder (APA, 2013). The APA (2013) further indicates that some of these disorders are also listed under personality disorders. The diagnosis of schizophrenia therefore relies on the advanced DSM criteria as mentioned earlier.

2.5 CULTURAL BELIEFS AND MENTAL ILLNESS

Jong (2003:27) asserts that Africans strongly believe in ancestors that transmit supernatural forces. It is explained that to Africans:

Gods or ancestors of a given culture form a scheme which interprets the vast diversity of everyday experiences in terms of the action of a relatively few kinds of forces, each category of beings having its appointed function in relation to the world of observable happenings.

Africans value their tradition and culture as it is a means of explaining everyday life events. They believe that nothing happens by chance, but that everything is pre-planned by their supreme beings. Stevenson (Makau, 2003:12) asserts that cultural beliefs carry explanatory value for human personality and biology which current theories cannot adequately clarify. This takes the study to the heart of the matter in terms of exploration of beliefs held about illness and disease. The perception of disease in African culture is highly influenced by ancestral beliefs. The notion of disease being caused by witchcraft is pointed out by Jong (2003:33) and he states that influences by the evil eye also causes illness and disease.

Jong (2003:27) further explains thoroughly that disease is caused by irate supernatural forces, by other human beings (witchcraft), by behaviour of an individual or his family, and by unpleased ancestors. Disease can also be due to loss of vital substances from the body, introduction of foreign or harmful substances into the body, natural causes (God), violation of taboos, and angry supernatural forces. The aspect of angry ancestors is emphasised with the fact that Africans are expected to perform certain rituals for their ancestors when instructed to do so, hence failure to obey such instructions lead to illness. Interventions by spirits are normally considered as revenge for ceremonial negligence of ancestors. McInnis and Merajver (2011:168) agree with Jong (2003) and state that disease, specifically mental illness, may be considered to be brought about by evil spirits or other forces, internal or external, in a combination of the personal and supernatural. Mental illness is often regarded as being founded in the dynamics of persecution. This perception of mental illness is primarily a form of persecution which stems from witchcraft activities, for example actual attacks of depression are attributed to persecution.

Jong (2003:33) asserts that Africans perceive ancestors as supreme beings that provide them with protection, wealth and offspring. They further believe in the notion of reincarnation whereby after one's death the soul of the deceased will reincarnate in another generation. The reincarnation is thought of as improving understanding of issues or events such as mental illnesses, including but not limited to phobias and depression. Jong (2003:28) delineates the theory of disease among Africans as disease being caused by superior beings such as gods or ancestors. These supreme beings are thought to be responsible for the occurrence of major human processes such as child birth, marriage, sickness, disease, and death. These factors are thought of as being caused intentionally by ancestors. Makau (2003:13) builds on Jong's point by adding that the cause of disease might be as a result of failure to appease ancestors with sacrifice or thanksgiving for purposes of protection or wealth. It is further indicated that like indigenous Western languages, Africans have their own terminology for diseases such as *ufufunyane* (alien spirit possession), *isidlliso* (somatic symptoms) and *ukuhlanya*

which is used interchangeably to explain madness, mental illness or mental retardation (Ellis, 2004:92).

The researcher is of the opinion that African culture is an interesting subject that needs deeper studies and understanding. Africans value their heritage and trust their cultural belief systems to guide them in everyday lives and experiences. These belief systems can be attached to an explanation of life attitudes as posed by Africans. Explanatory theories are provided for illness in cultural context by Africans, thus confirming that Africans do believe in supreme beings that are responsible for different events or occurrences in their lives. The researcher further believes that these belief systems are to be respected by health care professionals. As a means of being able to understand the client from their own cultural perspective, adequate knowledge needs to be obtained on the clients' specific cultural perspectives.

As discussed earlier, mental illness can be caused by witchcraft, angry ancestors or natural forces. The researcher notes that it can therefore be deduced that different individuals present with different symptoms. People living with mental illness are thought of to be possessed by evil spirits. This form of spiritual possession in an individual is more readily regarded as insanity caused by witchcraft. Traditionally, such insanity is viewed as the result of magical substances or stronger medicine used by somebody else (Labuschagne et al., 2003:110). The notion of witchcraft among Africans is believed to be engendered by jealousy. When one does not want to see others succeed in life, it may lead to overshadowing them with stronger medicine or substances that cause them to be insane or mentally ill, causing dysfunction in their lives (Labuschagne et al., 2003:110). An example is children thought to be intelligent at school or taking good care of their parents suddenly being incapable of their abilities as a result of being bewitched by jealous neighbours.

Manifestation of the disease presents itself differently from one individual to the next. It is argued that the bewitched person starts to mumble, talks in an incoherent or delirious way as if he/she is in a discussion with someone, talks to himself/herself, or starts to

wander around aimlessly. Jong (2003:33) is in consensus with McInnis and Merajver (2011:168) and states that when an individual is in a trance, the spirits transmit messages through a language unknown to ordinary human beings, which can be interpreted by a healer.

The researcher is of the opinion that there is definitely an overlap of symptoms from both the African and Western perspective. This poses a challenge in terms of making accurate diagnosis. The cultural aspect of the presenting symptoms needs to be understood from the client's experiential world in order to make an accurate diagnosis. In Western context, the symptoms would easily be diagnosed as schizophrenia considering the seriousness of the hallucinations and delusions, which in an African context is merely communication from ancestors. The researcher further points out that the symptoms discussed by Makau (2003:09), McInnis and Merajver (2011), and Labuschagne et al. (2003:168), amongst others, are attributed to communication by ancestors, witchcraft, or merely natural forces. This is again considered as symptoms of schizophrenia in Western context, considering that the patient will meet the DSM criteria.

With the above-mentioned diagnostic challenges stated by the researcher, it is imperative to probe the treatment options considered by Africans in such circumstances. The researcher believes that it would make sense that Africans would seek assistance from an individual who understands their culture and in whom they trust, normally a traditional healer. Traditional healers or witchdoctors have different skills and names in an African context, such as *Ngaka*, *Inyanga*, *Sangoma* or *Igqira*, (Ellis, 2004:107). Their skills range from dream interpretation and consultation with ancestors, to reversing witchcraft curses (Curationis, 2002:213). Labuschagne et al. (2003:108) add that consultation with a traditional practitioner may be required for dream interpretation.

Ngong (2000:52) argues that even though alternative treatments to mental illness are introduced to Africans, consultation with traditional healers is still considered the best

and only way to resolve their misfortune, because they believe that only traditional healers can communicate with the ancestors thus limiting the skills of Western health professionals. Curationis (2002:213) also adds that only traditional healers can connect with ancestors, thus leading Africans to opt for such a consultation to seek the reasons for the ancestors' anger or clarity on their message. Jong (2003:33) states that the witchdoctor has powers to reverse sorcery or witchcraft curses. They are the healers considered to have second sight which is normally an ideal skill that would encourage consultation from clients. Witchdoctors are able to drive out spirits (exorcism) from the clients through a process of getting into a trance and communicating with such spirits. Witchcraft can also be treated with herbs or roots (Jong, 2003:33).

Jong (2003:30) indicates that when an individual is faced with suffering and fails to receive treatment from a traditional healer, they then resort to Western health sectors for alternative treatment options. Within these sectors there are different interpretations reflecting different systems of meaning and norms for disease. Ellis (2004:108) adds that Africans also prefer dual consultation whereby the traditional healer will be consulted for supernatural causes and explanations and the Western doctor for symptomatic relief. Factors influencing the decision as to whom to consult between the traditional healer or Western doctor or even both, is dependent on access, degree of westernisation, level of education, socio-economic position, and influence of relatives and friends (Ellis, 2004:108). This supports the statement by Mosotho et al. (2008:171) that Africans consult traditional healers because family members encourage them to do so as it is family tradition. Furthermore the other reason is that Africans also believe that Western treatments are expensive, therefore catering for Western individuals or middle to upper class individuals.

When seeking Western treatments in relation to their presenting symptoms, the individual who is bewitched or possessed is likely to be diagnosed with schizophrenia because of the overlap of or identical symptoms (Labuschagne et al., 2003:109). Because mental health professionals within the Western context are trained to detect symptoms associated with mental disorders, they only focus on the presenting

standardised symptoms (Mosotho et al., 2008:171). Mental health professionals often lack training in differentiating between various culturally related syndromes and symptoms. This is especially important in multicultural countries such as South Africa where there is a dearth of information about cultural differences in the manifestation of mental disorders (Mosotho et al., 2008:171). Jong (2003:34) urges that health professionals need to be trained on the cultural aspects of disease on a preventative rather curative aspect, in pursuit of addressing health challenges with multi-cultural facets. Understanding cultural syndromes is over-emphasised to point out the value of knowing the cultural backgrounds of clients in order to be able to provide satisfactory services.

Culture plays an important role in people's lives, as it shapes society. Matthews (2010:02) defines culture as a set of shared norms, standards and expectations by a specific group of individuals. Africans have their own cultural beliefs that shape their day-to-day lives. Culture is influential in the decision-making process and the way Africans perceive specific issues. Health problems are considered a form of communication from ancestors to the people (Curationis, 2002:214). The result is that Africans consult traditional healers to seek a clear understanding of the ancestors' communication.

There are different explanations of health problems in the African context itself (Makau, 2003:10), thus the aim of the study is to explore the cultural beliefs of caregivers of adult children living with schizophrenia. This study explored the cultural beliefs of parents as caregivers of adult children living with schizophrenia. The interest in this study was motivated by the notion that African culture is not clearly understood in relation to schizophrenia. Schizophrenia carries many symptoms which, in an African context, are not necessarily attributed to a disease.

Most of the research studies conducted by authors such as Makau (2003) and Curationis (2002) focus on Western culture. The studies on African culture focus more on treatment options than the reason for opting for such treatments. The gap in these

studies is that the causal belief systems for mental illness in African cultures have been largely overlooked. Such beliefs include the belief that mental illness is caused by witchcraft, for example. The lack of researched knowledge, facts and awareness on the different causal factors of mental illness in African cultures increases the likelihood that Africans will seek traditional assistance in terms of managing mental illness, as it is the only trusted option they are knowledgeable about. The holistic context of culture in relation to mental illness is not explored, especially schizophrenia as it is highly prevalent in African communities and largely thought of as being caused by witchcraft (Makau, 2003:42).

The overlap between the symptoms of schizophrenia in Western culture and those of communication by the ancestors in an African context makes it imperative to make a distinction between the two. A distinction can only be made through a thorough study and concise understanding of African culture in relation to schizophrenia. The best way to achieve this goal is by engaging with people experiencing this phenomenon; thus the study aims to explore the cultural beliefs of caregivers of adult children living with schizophrenia with an aim of shedding light on the phenomenon. With the process of deinstitutionalisation in South Africa post-apartheid, family members have been the primary caregivers for their loved ones living with schizophrenia. It is thus evident from the experience period of exposure to caregiving responsibilities that the caregivers are a plausible target population for the study.

2.6 CAREGIVERS' EXPERIENCES AND CULTURAL BELIEFS REGARDING MENTAL ILLNESS

Families of origin remain the most important social contact and source of support for the majority of schizophrenia patients (Public Health, 2013). The caregivers are responsible for the physical, emotional and social wellbeing of family members living with schizophrenia. The primary symptoms of schizophrenia in Western contexts include hallucinations and delusions (Barlow & Durand, 2009:476) whereby in an African

context mumbling to oneself or seeing people that are invisible to others is considered as communication from ancestors or witchcraft (Makau, 2003:13).

Families of people living with schizophrenia have a major influence on their lives as they determine how they perceive the illness, which usually would be interpreted in a cultural way. This is because relatives of families of people living with schizophrenia have been raised in such a manner that when one is faced with illness or disease, it means the ancestors are trying to send a particular message. This is a way of living for the African population (Public Health, 2013).

The notion of hallucinations and delusions in the African context is classified as madness (Makau, 2003:09). It is argued that ancestors communicate with their next of kin in the form of dreams, voices or visual messages that can only be seen by the person whom the message is sent to, which the Western world defines as hallucinations or delusions (Labuschagne et al., 2003:108). Usually caregivers as primary carers are the first to notice such behaviours and, depending on the type of messages received, they have to make a decision on how to deal with or respond to it. With the assistance of elders, caregivers are responsible for ensuring that proper cultural practises are followed and adhered to. In some cases where there is resistance to follow the orders sent in the messages, inexplicable events occur, such as an illness (usually mental) or a series of misfortunes (Labuschagne et al., 2003:108). Ngong (2000:28) argues that some Africans believe that mental illness is a punishment from the ancestors if there is disobedience, such as failure to perform specific rituals.

Families that have a member who is diagnosed with mental illness, specifically schizophrenia, experience stigma in the community as the family will be viewed as cursed, leaving little respect and recognition for the mentally ill individuals (Ngong, 2000:30). Caregivers are affected the most as they sometimes struggle to get assistance and support from relatives and community members. Often others are willing to assist or offer support, but are afraid of being associated with the cursed family,

afraid to be stigmatised by the community due to their association with the cursed family, and afraid that the curse might also affect them (Ngong, 2000:30).

Caregivers are forced to adjust to different coping mechanisms with a range of family challenges, including emotional and financial strain (Pilgrim, 2009:90). The emotional climate of the family can affect relapse for individuals with schizophrenia and role tension for the caregivers. This might itself lead to family members, especially parents, abusing those diagnosed with mental illness that they are taking care of. The abuse can take the form of blaming the individual living with schizophrenia for bringing the curse on the family and favouritism of other siblings who are mentally fit (Pilgrim, 2009:91). Often times, other caregivers believe that their children are being punished for the parents' disobedience to the ancestors, hence bringing self-blame on the caregivers' side (Pilgrim, 2009:91). Videbeck (2009:291) adds that families as caregivers of people living with schizophrenia are responsible for the psychosocial needs of the member living with schizophrenia. Depending on the severity of the illness, the caregivers may be responsible for the provision of basic needs including feeding, bathing, dressing and potty training.

Other responsibilities include administering medication and ensuring that the member adheres to medication. This is sometimes a challenge as members sometimes do not want to take their medication. Videbeck (2009:291) further asserts that role strain poses a challenge especially when caring for adult children. Financial challenges include transportation, traditional healer or doctor's consultations, and after care services. Caregivers of people living with schizophrenia are directly involved in the treatment processes of their families. This is because they are usually the main decision-makers as caregivers. When individuals living with schizophrenia consult with a traditional healer, they are accompanied by a relative or family member for explanation of the symptoms to the traditional healer and for reporting back to the family elders after consultation (Ellis, 2004:107).

The researcher deemed her community of origin as a suitable research site as she understands the historical background of the community and has been exposed to issues of mental illness in the area. The South African Government also recommends that researchers should focus on their immediate areas when conducting research to meet the needs of their own communities, rather than elsewhere (Mosotho et al., 2008:172). The researcher is also compatible in terms of the home language of the participants, which will encourage a clear communication process during the data collection.

It is clear that Africans deem culture very valuable in terms of explaining illness and disease in their lives. Ancestral powers and abilities are held highly in terms of resolving illnesses and disease. The researcher is of the opinion that the exploration of caregivers' experiences is central to understanding the phenomenon of schizophrenia. Careful consideration of cultural explanations and environmental factors play a vital role in this instance. Pilgrim (2009:179) argues that mental illness may be shaped by expression, incidence and prevalence by cultural differences. Health care workers should be very careful to understand cultural meanings such as folk beliefs when making any diagnosis (Pilgrim, 2009:179).

Pilgrim (2009:180) further asserts that there are of course challenges regarding cultural sensitivity. Firstly, too much cultural sensitivity threatens the core assumption of a universally stable body of knowledge. Secondly, under-emphasising cultural sensitivity will result in health practitioners being accused of being culturally insensitive or manifesting a form of Western cultural pluralism, with the use of Diagnostic Statistic Manual of Mental Disorders already an example of this. Besides the challenges outlined, criticism of cultural sensitivity allows for health care workers to be more sensitive to alternative belief systems and contextual reasoning. This invites health practitioners to pay close attention to the particular meanings being expressed by an individual patient, putting their cultural beliefs in context.

2.7 INTERNATIONAL LEGAL FRAMEWORK ON MENTAL HEALTH

Legal frameworks provide guidance and planning steps for improved service delivery. The legislation of governing countries are recognised as legal statutes that all citizens have to adhere to. Failure to comply with legal statutes results in legal actions being taken. It is the countries' responsibilities to ensure that promulgated legislative frameworks are effectively implemented and carried out through monitoring and evaluation processes. Below are discussions on the recognised international and national legal frameworks.

2.7.1 Alma Ata: Primary Health Care Declarations

From 6 to 12 September 1978 an International Conference on Primary Health Care Alma-Ata was held by major states in a bid to promote the health of all people in the world. The declarations affirmed that health is a state of complete physical, mental and social wellbeing and not merely an absence of disease or infirmity, thereby making it a fundamental human right (Alma Ata, 1978). This led to the notion that the highest level of health should be attained world-wide. All governments were urged to formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system (Alma Ata, 1978).

Mental health was under the umbrella of the health care system and focused mainly on the promotion of better mental health care systems and access to mental health care resources. Families were recognised within the declarations as the main providers of health care, with women being the main caregivers as they hold central roles within the family systems. Empowerment of family structures, especially the main caregivers, was advocated as they play an important role in health promotion (Alma Ata, 1978).

The humane treatment of mental health care users was advocated in line with the human rights approach as declared in the African Charter on Human and Peoples' Rights. Mental health policies and legislation were promulgated with the first approach

of getting rid of exorcisms and asylum detainment of mental health care users in certain states such as South Africa (WHO, 2012).

2.7.2 The United Nations Millennium Development Goals

The Millennium development goals were promulgated in a bid to rid the world of extreme poverty. In September 2000, 189 leaders assembled to sign the eight millennium development goals to combat poverty, hunger, disease, illiteracy, environmental degradation, and discrimination against women (WHO, 2012). Universal health care was part of the goals to be achieved, as health is regarded as a fundamental human right. It is evident that by the year 2015 most of the countries did not meet the specified level of goals as set in 2000, but with the assistance of the United Nations Development Programme's expert advice, training, and grant support to developing countries, the 189 states have made significant progress in some areas of the set goals. The goals are in line with the objectives of the African Union to promote and protect human rights as mandated in the African Charter on People and Human Rights. A move to better social conditions is advocated for by all these declarations with annual monitoring of progress to evaluate the stage of goal achievements (United Nations Report, 2006). Countries or states that derail from the goal attainment are to seek assistance from other states such as International Financial Institutions. Each state is therefore expected to produce an annual report on its state of affairs in terms of the progress of meeting the set goals (United Nations Report, 2006).

2.8 NATIONAL LEGAL FRAMEWORK

South Africa witnessed the birth of its crucial post-apartheid policy legislations through the adoption of the Constitution of the Republic of South Africa (RSA, 1996) along with the Bill of Rights in 1996 and enforced them in 1997 (McCrea, 2010). These policies motivated the reorganisation of the Health Care System with the patronage and advocacy of the WHO (Pilgrim, 2009:24). In the same year (1997) a chapter on mental

health was included in the Department of Health's White Paper for the Transformation of the Health System in South Africa (Mental Health and Poverty Project, 2008).

2.8.1 National Policy

2.8.1.1 *The Constitution and Bill of Rights*

The Constitution of the Republic of South Africa was approved by the Constitutional Court on 4 December 1996 and took effect on 4 February 1997. The Constitution is the supreme law of the country and no other law or government action can supersede its provisions (RSA, 1996). The Constitution is based on the values of democracy and social justice, thereby fostering an environment where citizens are equally entitled to the rights and privileges of citizenship (RSA, 1996). Amongst these rights is the right to equality which instructs that no citizen should be unfairly discriminated against, directly or indirectly on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, or birth (RSA, 1996). It is also stated that everyone has inherent dignity and the right to have their dignity respected and protected (RSA, 1996). It is for this reason that mental health care users as citizens of the country are entitled to equitable services and access to resources despite their mental incapacity. Mental health care users are to be treated with respect and dignity, not classifying them according to their illnesses. Their right to dignity is respected as they are now identified as mental health care users instead of previously derogatory and labelling terms such as “mentally ill people”, “mad people” or “retards”. However, the researcher notes that there is minimal positive progress in terms of classification of people living with mental illness.

2.8.1.2 *The Policy Framework and Strategic Plan 2013-2020*

After the 1994 elections, the process of deinstitutionalisation was set in motion, resulting in less restrictive care facilities and options for mental health care users. Mental health was receiving attention and reports show that mental health legislation and policy has progressed since 1994. The National Mental Health Policy Framework and Strategic Plan 2013-2020 was promulgated after the realisation that despite the improvement of

mental health services, there was still great challenges as a result of social determinants of mental health, including but not limited: to poverty, unemployment, and substance abuse (Department of Health, 2013).

The National Mental Health Policy Framework and Strategic Plan 2013-2020 is a strategy that seeks to enhance participation of mental health care users and their families. This is evident in the consultative process that was undertaken during the promulgation of the policy framework (Department of Health, 2013). All nine South African provinces held summits to review the state of mental health and mental health services within their borders, to identify best practices and to generate a road map for improving mental health. Data was gathered through interviews with key informants selected from the different spheres of Government. The study results indicated that mental health care users were slowly being identified as equal citizens with equal rights. Furthermore, access to resources and advocacy of mental health services was more active even reaching destitute rural areas. The process of the policy also shows evidence of consultation processes of mental health care users and their families through the data collection processes indicated above whereby all nine provinces were divided into segments to collect data from recipients. Nonetheless, the results also showed areas of developments especially in the awareness and education about mental illness especially to Africans in rural communities.

The International guidance materials by the WHO informed both the content and format of the National Mental Health Policy Framework and Strategic Plan 2013-2020 (Department of Health, 2013). These consultations culminated in a national mental health summit where a draft of this Policy Framework was discussed (MHPFSP, 2013-2020). The Policy Framework advocates for the rights of mental health care users through identification of key activities that are considered catalytic to further transform mental health services and ensure that quality mental health services are accessible, equitable, comprehensive and are integrated at all levels of the health system, in line with WHO recommendations (MHPFSP, 2013-2020).

2.8.1.3 The White Paper for Social Welfare

The White Paper for Social Welfare (RSA, 1997a) is etched on the premise of developmental social welfare. It aims to promote a humane, social and just society, facilitate the meeting of basic human needs, and promote full participation in social, economic and political spheres to build human capacity and foster basic self-reliance. The White Paper for Social Welfare seeks to promote developmental social welfare to all citizens, especially those living in conditions of poverty and vulnerable groups. Its principles are based on the equity of services and non-discrimination of people, including those living with mental illnesses (RSA, 1997a).

The establishment of the policy has highlighted barriers within the country, thus a primary mode for the delivery of services was proposed. The proposed strategy was to establish one national department and nine provincial departments for social welfare, with each area's roles and responsibilities being clarified, and mechanisms put in place to ensure harmonious and effective working relationships. The breaking down of provinces was to ensure that services reach all citizens, as it will be easier to monitor the process in segments than in one national department (RSA, 1997a).

The researcher points out that the White Paper's involvement in communities at local level plays a crucial part in developmental services, as the people on ground level can get an opportunity to express their needs and opinions regarding health services, especially mental health services, from their own first-hand experiences, which aids in effectiveness of services implemented. The researcher used the policies as a cornerstone in terms of exploring the perspectives of caregivers of mental health care users to ascertain that policy implementations would address mental health care user's needs. The research study further strengthens the objectives of consultation, redressing needs for mental health care users and access to resources. Post 1997, mental health care users were treated as humane as possible with the system of asylums and exorcisms being totally abolished. The researcher is of the opinion that the current state of affairs in terms of mental health care users has greatly improved as they are included as recipients of citizen benefits and social support such as social grants, mental health

organizations that address the needs of mental health care users, remedial services and medical treatment and support in public institutions.

2.8.1.4 *The White Paper for the Transformation of the Health System*

The White Paper for the Transformation of the Health System in South Africa fosters a comprehensive and community-based mental health and related services. It is founded on the core themes of evaluating the prevalence and problems of mental health issues in order to promote effective strategies in response to such challenges. The advancement and restructuring of mental health is propagated through a systematic process of development and monitoring of norms and standards and research opportunities in this field. Since South Africa is a diverse country, the place of traditional healers within the health care system is not overlooked, but instead traditional healers are included as part of the multi-disciplinary team within the mental health care scope (RSA, 1997b). This shows a respect for cultural beliefs as the White Paper explores the nature and extent of collaboration with traditional healers to ensure that all cultural spheres of mental health are accounted for.

2.8.1.5 *The Mental Health Care Act 17 of 2002*

The South African Government set up strategies to monitor procedures regulating services rendered to mental health care users. These strategies encapsulated the Mental Health Care Act 17 of 2002. The Mental Health Care Act (No. 17 of 2002) is aimed at:

...providing for the care, treatment and rehabilitation of persons who are mentally ill; to set out (different procedures to be followed in the admission of such persons); to establish Review Boards in respect of every health establishment; to determine their powers and functions; to provide for the care and administration of the property of mentally ill persons; to repeal certain laws; and to provide for matters connected therewith.

The value of social justice is the cornerstone of the Mental Health Care Act (No. 17 of 2002) as it regulates fair and equitable services to mental health care users. This is supported by the Mental Health Care Act's core objectives of ensuring that services be accessible and available to the population equitably, efficiently and in the best interest

of mental health care users within the limits of the available resources. It further emphasises the co-ordination of access to mental health care, treatment and rehabilitation services to various categories of mental health care users in respect of their rights and obligations (Mental Health Care Act 17 of 2002). It is to be noted that the notion of equal and just services are treading on the trails of the Bill of Rights of no discrimination in terms of service delivery to citizens as the act mediates for equal services for mental health care users of all categories.

It is to be noted that there is an existence of an array of policies for health care globally. These policies are aimed at addressing the needs of people in order to foster an environment of quality of health. Policies at both national and international levels are continually monitored in order to evaluate if the needs of people are adequately addressed and also to make amendments where necessary. The promulgation of policies for mental health care services ascertain that mental health needs are publicly exposed and addressed, although there still exists some challenges. Mental health policies have ensured the equal treatment of mental health care users with the process of deinstitutionalisation being at the peak of success for humane treatment of mental health care users.

The researcher is of the opinion that legislation and policies are crucial for service delivery to citizens, as it fosters a systematic process of thorough planning, implementation and monitoring in a bid to cater for the rights of people. It is therefore to be noted that a bottom-up spiral of communication should be fostered whereby citizens are consulted by local government institutions to provide detailed data on services, needs and experiences. This data will ensure the effectiveness of the scope of legislation as it will address relevant needs as proposed by the public. It is further pointed out by the researcher that encouragement of national research opportunities should be fostered and funded whereby the public can have opportunities to share their experiences and needs in terms of services rendered to them, especially in the field of mental health. These opportunities for the public will be controlled as the researchers will be suitably qualified to undergo such studies.

2.9 PROGRAMMES FOR PARENTS AS CAREGIVERS RAISING ADULT CHILDREN WITH SCHIZOPHRENIA

One of the identified ways of rendering services within the community segments was through community development. With the deinstitutionalisation process that took place post-1994, the shift to community development was mandated. The choice of community development was to ensure that mental health care users remain within their communities where they would receive maximum support and interventions within the comfort of their familiar surroundings (RSA, 1997a). Community development strategies were deemed necessary as they seek to address basic material, physical and psycho-social needs, in turn reorienting social welfare programmes towards comprehensive, integrated and developmental strategies (RSA, 1997a).

Community development is a multi-sectorial and multi-disciplinary process as it involves the Department of Health personnel, community care workers, families, churches, traditional healers, and other community institutions which are all focused on a mentally healthy society through cooperation to assist those living with and affected by mental illnesses. The multi-focal involvement of community development strategies also serves the purpose of reducing stigma within the communities with regard to mental illness (RSA, 1997a).

Community development programmes focus on the facilitation of the community development processes, the development of family-centred and community-based programmes and the facilitation of capacity-building and economic empowerment programmes. These programmes will foster a full cooperative strategy that will aid effective service delivery to mental health care users along with their families. Greater attempts are made to promote transparency of the community development programmes and services to mental health care users and their families through awareness and educational programmes. Mental health care users and their families

are therefore involved in consultation processes and information giving sessions whereby they contribute to policy-making processes (RSA, 1997a).

The researcher is in full support of the community development programmes for mental health care users along with their families. It is strongly believed by the researcher that treatment of mental illness from familiar environments will foster restoration of health through stabilisation and moral support received from family members and community members. The researcher is of the notion that keeping mental health care users in the community will also assist in addressing stigma, as it will promote positive attitudes amongst community members as they will be exposed to mental health care users. The involvement in their wellbeing strategies will also provide insight to community members on what mental health care users are experiencing. It is further pointed out by the researcher that educational programmes will empower mental health care users with information on mental illness and how to cope with it, while for community members it will empower them with information on how to support and treat those living with and affected by mental illness.

2.10 THE CHALLENGES OF RAISING ADULT CHILDREN WITH SCHIZOPHRENIA

Caregivers of mental health care users range from parents, siblings and relatives, to the wider community members. Parents are usually the first to take on the responsibility of caring for their children who are living with a mental illness. Although most attention is given to the mental health care user, it is important to also look into the challenges faced by those caring for mental health care users. Parents as caregivers of mental health care users face a set of challenges such as emotional, financial and physical challenges. The White Paper for Social Welfare (RSA, 1997a) states that the financial, social and emotional resources of families are strained when they have to care for members who have special needs and problems. Below the noted challenges experienced by parents as caregivers of adult children living with schizophrenia are discussed.

2.10.1 Psychological challenges

Potgieter and Heyns (2006:548) state that the diagnosis of a disabling disorder, in this context mental retardation or mental illness, causes an array of negative emotions for families, especially for parents, including denial, shock, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment, and fear. Anxieties and worry about the future has been a notable feature whereby parents as caregivers would be worried about who will take care of their children if anything were to happen to them. Parents experience fear that their loved ones would not get adequate care should anything happen to them. The fear of relapse or defaulting on medication remains one of the core issues. Caregivers further experience feelings of depression, as they do not have any form of assistance and support. Greater worries relate to finances, adequate housing, and administering and monitoring of medication by the mental health care users (Potgieter & Heyns, 2006:548).

2.10.2 Physical challenges

Butler (2008:1260) stipulates that negative emotions adversely affect the physical health and wellbeing of caregivers, which may result in a reduced life expectancy. The responsibility of caring for mental health care users is strenuous and time-consuming, thus resulting in less time on self-care for caregivers. Caregivers have limited time for personal care activities, exercise and good nutrition. Thompson and Gallagher-Thompson (2007:947) maintain that although physical fitness differs from one caregiver to the next, insufficient sleep, poor nutritional regimen, and lack of physical exercise contributes to caregivers' decline in general health. Depending on the level of functionality of the mental health care user, caregivers are sometimes expected to perform basic tasks such as bathing, feeding and moving of mental health care users, which may require extra physical strength. The researcher believes that the fact that most caregivers are women and lack the physical strength of their male counterparts, the issue of muscle strain can also result from these activities. Somatic symptoms such as headaches have also been reported by caregivers which are a sign of ill-health itself.

2.10.3 Social challenges

Families of mental health care users, especially those of people living with schizophrenia, are isolated for a number of reasons which include stigma from the community or feelings of embarrassment from the side of the family. Lefley and Hatfield (1999:369) indicate that caregivers lack support from the health system and the communities at large while caring for their loved ones. These families present with lower levels of psychological wellbeing, poorer relationship with their offspring, and greater behavioural problems from their offspring. Ivey et al. (2012:807) assert that caregiving may be shaped by culturally-based views about the roles of caregivers and recipients, thus influencing the choice of caregiving styles. These caregiving beliefs further influence the caregivers' decisions to receive or refuse assistance from external sources.

Caregivers experience role overload as there are role changes within the families. Adult children who are supposed to be responsible for specific chores and duties within the families are the ones that need care, thus their roles are transferred to their caregivers. Balancing caregiving roles within the family along with a personal lifestyle is associated with stress and burden for caregivers (Lai, 2010:201). Parents are culturally expected to take care of their families, especially mothers, hence most caregiving responsibilities are carried by mothers within households. This puts strain on them as they might be under the pressure of normal household chores along with the care of the mental health care users (Ivey et al., 2012:809). Scharlack, Li and Dalvi (2006:626) add that role changes often cause family dysfunctions.

2.10.4 Financial challenges

As recorded earlier through the White Paper for Social Welfare (RSA, 1997a), caring for family members with special needs strain the family's finances and economic wellbeing. Roberto and Jarrot (2008:102) indicate that caregivers are often forced to manage employment and caring responsibilities to be able to meet their personal financial needs and the financial needs of caring for their loved ones. Being employed as a caregiver becomes challenging, as caregivers have to occasionally apply for leave days at work

which results in loss of income, or worse, might even result in loss of employment. Employed caregivers also face the challenge of seeking suitable day care facilities to care for their loved ones while they are at work which is an extra cost on its own.

From the above discussions it is evident that caregivers are in dire need of support in their specific endeavour of caregiving. The researcher strongly emphasises that greater support programmes and community development programmes, as quoted in legislative policies such as the White Paper for Social Welfare (RSA, 1997a), need to be implemented in aid of caregivers whereby they will receive training and support on healthy coping mechanisms. Psycho-education programmes should also be promoted with a dual purpose of empowering mental health care users and caregivers concurrently.

2.11 THE ROLE OF SOCIAL WORKERS IN ASSISTING CAREGIVERS OF ADULT CHILDREN WITH SCHIZOPHRENIA

Potgieter (1998:169) asserts that the role of the social worker aims to improve the social functioning of a system by assisting them to understand their attitudes, subjective perceptions and feelings to modify behaviour and teach them to cope with problematic situations.

- **Community change agent:**

A community change agent seeks to improve or restructure the community's needs through a planned process of problem identification and implementation. The inclusion of community members is achieved through discussions and interviews when soliciting information regarding the community (Zastrow, 2007:77). The community change agent assists community members to access resources so that they can meet their life functioning goals. The researcher is of the opinion that social workers as community change agents can assist families to care for people living with mental illnesses to access information regarding mental illness psycho-education. This can be achieved through various forms of

education, depending on the literacy levels of the audience, such as planning and implementing health talks, small group discussions, support groups, and seminars.

- **Enabler**

Zastrow (2007:77) states that an enabler helps individuals or groups to articulate their needs, to clarify and identify their problems, explore resolution strategies, to select and apply strategies, and to develop their capacities to deal with their own problems more effectively. The researcher is of the opinion that community members can be involved in the problem identification processes by the social worker as primary participants. The social worker can assist community members through a process of enabling them to be able to express their needs through research or community needs analysis processes. Communities will then be trained on how to address their identified needs with the use of available resources or through access to external resources.

- **Broker**

Zastrow (2007:77) asserts that a broker links individuals and groups who need help with community services. The researcher believes that social workers can assist in linking community members with necessary resources, such as mental health educational and support groups to foster empowered community members. The social worker can also assist community members with information on services available to them that they were not aware of and how to access them. Community members can be linked with professional health care workers, such as psychiatrists, support workers and donors, which can aid in mental health services.

- **Empowerer**

An empowerer assists individuals and families to realise their potential and use existing strengths and resources to solve their life challenges (Zastrow, 2007:77). The researcher believes that communities can use available resources and

manpower to address some of the challenges they experience, for example social workers can empower community members to form strong caring and support groups whereby they can assist each other with caring activities to resolve their own problems through sharing their unique experiences with the facilitative role of the social worker. Community members can further be empowered to start a day care centre where community members can take turns to care for people living with mental illnesses instead of paying for day care centres.

2.12 SUMMARY

In summary, it is evident that schizophrenia has detrimental effects both on the individual and the family. Understanding mental illness challenges is a multi-faceted process requiring multi-sectorial and multidisciplinary approaches. Culturally, the issues of cultural diversity and belief systems have to be considered in terms of understanding the syndrome of schizophrenia. The researcher believes that because culture shapes society and influences the way people react to their environments, it is only plausible to first consider that which Africans hold true to themselves as reality. Makau (2003:13) asserts that Africans value their heritage and trust their cultural belief systems to guide them in everyday lives and experiences. These belief systems can be used as explanatory theories attached to life attitudes and behaviours as posed by Africans. Cultural sensitivity is an evident process in understanding the mental illness in African contexts.

Labelling of mental health care users as retards or mad people and denial of services to such groups show evidence of prejudiced behaviours from larger communities. People living with mental illness deserve to be treated with dignity and respect, despite what they suffer from. It is for this reason that national and international legislative frameworks such the Constitution and Mental Health Care Act were promulgated with the aims of equitable services, human rights advocacy, and dignified treatment of people living with mental illnesses. These legal frameworks are in line with the value of

social justice as a cornerstone for social work services. Social work services seek to achieve human rights for people through advocacy of equitable service and resources.

Barriers to mental health services and challenges experienced by both individuals and families can be addressed through various process set out by the national and international Government statutes. The multi-sectorial and multi-disciplinary community development programmes as set out by the White Paper for Social Welfare (RSA, 1997a) seek to address mental health barriers by linking all stakeholders in a bid to diversify equitable resources and access to support systems. The family intervention strategies devised by Mari and Streiner (Anderson & Adams, 1996:505) expand on community development programmes by adding aspects of family psycho-education, support services and skills development services for families and relatives of those living with mental illnesses.

This study explored the experiences of parents as caregivers of adult children living with schizophrenia in a rural African community. The researcher is confident that the findings of the study as will be discussed later on in Chapter Three will provide factual information on the belief systems held by Africans in explanation of mental illness, especially schizophrenia. The findings might breach the existent gap of studies on mental illness in reference to cultural belief systems. The next chapter will focus on the discussion and presentation of the research methodology, ethical aspects, empirical findings and the summary of the chapter.

CHAPTER THREE – RESEARCH METHODOLOGY AND EMPIRICAL STUDY

SECTION A: RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter outlines the research methodology and research design that guided the study. The choice of the research design that guided the study to achieve its objectives is also included. The discussions within the chapter include the research paradigm, investigative methods and data collection techniques. The chapter is concluded with ethical considerations and the role of the researcher within the study.

The goal of the study was to explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia at Mfihlakalo Day Care Centre in Pretoria. The objectives of the study are as follows:

- To conceptualise mental illness in relation to cultural beliefs in rural African communities.
- To describe schizophrenia and provide a description of the causes, types and symptoms.
- To describe the cultural beliefs of caregivers of adult children living with schizophrenia.
- To explore the needs and challenges of parents as caregivers of adult children living with schizophrenia.
- To make recommendations for the improvement of social work services provided to parents who are caregivers of adult children living with schizophrenia.

The research findings are later presented and discussed in form of themes to categorise the findings.

3.2 RESEARCH METHODOLOGY

Rubin and Babbie (2011:351) assert that samples in qualitative research are usually small and are often purposively selected and possess the advantages of flexibility, in-depth analysis, and the potential to observe a variety of aspects of a social situation. Creswell (2007:35) further indicates that qualitative research is centred around non-statistical methods of enquiry and analysis of social phenomena in which themes and categories arise through data analysis processes. Data is collected through the use of interviews, tape recorders, observations and field notes.

The research methodology is organised and structured under the following headings: the research approach, the type of research, the research design and methods, the feasibility of the study, and ethical aspects.

3.2.1 Research Approach

The study was qualitative in nature, as it sought to explore participants' belief systems and experiences. There are no adequate research studies conducted on the phenomenon of cultural beliefs and schizophrenia from caregivers' personal point of view. It is for this reason that a qualitative study was considered in order to collect the personal accounts, meanings and perceptions of parents as caregivers of adult children in relation to schizophrenia (Creswell, 2007:42). Nieuwenhuis (2007:51) indicates that qualitative research is concerned with understanding the process and the social and cultural contexts which underlie various behavioural patterns, and the emphasis is on the quality and depth of information provided. The exploratory nature of the study allowed the researcher to elicit in-depth information and insight from participants regarding their culturally influenced belief systems in terms of care giving experiences of adult children living with schizophrenia in a rural African community.

Babbie (2011:441) emphasises that qualitative research is characterised by its focus on understanding some aspects of social life, and its methods which generate words rather than numbers as data for analysis. This study was concerned with understanding

parents as caregivers' beliefs systems regarding schizophrenia, thus the focus on the social aspect of culture provided an in-depth understanding of cultural beliefs of parents as caregivers of adult children living with schizophrenia.

3.2.2 Research Question of the Study

The research study was guided by the following research question “***What are the cultural beliefs of parents as caregivers of adult children living with schizophrenia?***” The research question is derived from the research topic, making the theoretical assumptions in the framework more explicit (Welman, Kruger & Mitchell, 2005:52). The research question assisted in eliciting an understanding of schizophrenia from a cultural perspective as believed by parents as caregivers of adult children living with schizophrenia in a rural African community.

Bryman (2012:10) postulates that the research question forces the researcher to reflect on the central theme of the research study, while at the same time providing a clear platform and guidance to conduct the study. The research question is expected to be derived from the research topic, thereby avoiding derailing from the purpose of the study. The researcher derived the research question from the topic of the study. The research question was emphasised with a question mark to indicate its questioning value. In addition, the research question assisted the researcher to remain aligned to the purpose of the study.

3.2.3 Type of Research

The research study was based on the connotations of applied research. Bless, Higson-Smith & Kagee (2006:67) assert that applied research is exploratory in nature. The authors further assert that exploratory research is conducted to gain insight into a situation, phenomenon, community or individual. Neuman (2001:23) is in consensus with Bless et al. (2006) and further indicates that applied research seeks to assist in solving a particular problem facing a community. Bless et al. (2006:72) expand that the need for such a study could arise out of a lack of basic information on a new area of interest, with the goal being of improving human conditions. Babbie (2007:25) indicates

that applied research aims to solve practical problems or provide answers to useful questions regarding programmes, projects, policies or procedures.

The researcher points out that applied research was suitably applicable for the study as it assisted the researcher in eliciting information that will assist to resolve the problem of lack of understanding of belief systems in relation to schizophrenia as perceived by parents as caregivers of adult children living with schizophrenia. The study itself will not provide the solutions to these problems, but is a platform for recording the belief systems and experiences of caregivers. This will increase the opportunity of information dissemination so that cultural belief systems of caregivers in relation to schizophrenia can be publicised. The study also played a role in the establishment of recommendations in terms of schizophrenia as shaped by cultural belief systems of parents as caregivers.

3.2.4 Research design and methods

3.2.4.1 *Research design*

The choice of research design in this study was the collective case study, as the study was exploratory in nature. Creswell (2007:74) considers a case study as a methodology, strategy of inquiry, or a research strategy, with emphasis placed on its explorative and descriptive nature. Fouché (2011:321) identifies the case study as a method of research design involving an exploration of a “bounded system” or single or multiple case, over a period of time through detailed, in-depth data collection involving multiple sources of information. In this study the case might be bounded by time, place or context. The researcher opted for the collective case study in a bid to gather as much in-depth information as possible for rich data. The researcher collected data in the form of a collective case study comprised of parents as caregivers of adult children living with schizophrenia. The participants were bound by place and context, as the study was focused on rural areas within the context of cultural belief systems held by parents as caregivers.

Fouché (2011:322) stipulates that a collective case study is an instrumental case study extended to a number of cases whereby cases are chosen so that comparisons can be made between cases and concepts, thus enabling extension and validation of theories. To ensure background knowledge and information on the subject matter, the researcher explored literature on schizophrenia and African culture as perceived by caregivers, as supported by Creswell (2007:82) that the case study researcher seeks to enter the field with knowledge of the relevant literature before conducting the field research.

The researcher collected in-depth data from parents as caregivers of adult children living with schizophrenia who are attending Mfihlakalo Day Care Centre, in the rural area of Klippgat, Pretoria. The researcher was mainly concerned about the caregivers' cultural belief systems with regard to schizophrenia according to the meanings attached to it; therefore the researcher ensured appropriate data collection through the use of a detailed interview schedule to guide the data collection process.

3.2.4.2 Research population, sample and sampling methods

- **Population**

Strydom (2005b:112) states that population “refers to individuals in the universe who possess specific characteristics”, while Bryman (2012:418) refers to population as a totality of persons, events, organisation units, case records, or other sampling units with which the research problem is concerned. The researcher conducted the study at Mfihlakalo Day Care Centre in a rural community called Klippgat in Pretoria. The population for the study was parents who are caregivers of adult children living with schizophrenia. These are parents of adult children attending the Mfihlakalo Day Care Centre. The Day Care Centre is located within the community and is the only Day Care Centre that offers educational and aftercare services for adult children living with different mental illnesses (Ramatsu, 2014). The services rendered at the day care centre involve the physical, emotional and academic needs of these individuals, relieving parents as caregivers from caregiving responsibilities from 08:00 until 15:00.

- **Sampling**

Barker (2003:380) defines a sample as a small portion of the total set of objects, events or persons from which a representative selection is made. Unrau, Gabor and Grinnell (in Strydom, 2005b:212) describe a sample as a subset of measurements drawn from a population in which we are interested. Because there are a lot of children attending the school, the researcher selected a representative sample to participate in the study. The sample for the study was parents of adult children living with schizophrenia attending the Mfihlakalo Day Care Centre.

The researcher deemed non-probability sampling appropriate for the study, because the researcher does not know the population size or members of the population (Strydom, 2005b:212). Welman et al. (2005:106) state that non-probability sampling focuses on sampling techniques where the units that are investigated are based on the judgement of the researcher. Participants were selected by use of purposive sampling. Purposive sampling is composed of elements that contain the most characteristic, representative or typical attributes of the population that serve the purpose of the study best (Strydom, 2005a:302). Welman et al. (2005) point out that purposive sampling is also known as judgemental, selective or subjective sampling.

The researcher approached Ramatsu, the principal at Mfihlakalo Day Care Centre, to seek permission to interview parents who are caregivers of adult children living with schizophrenia. The researcher explained the purpose of the research, the ethical considerations, and discussed availability of the participants for information collection. The researcher did not have any contact with the participants prior to the data collection process. The researcher selected a sample from the available list of names with the assistance of Ramatsu. The first 12 parents as caregivers of adult children living with schizophrenia who met the criteria were selected to participate in the proposed study.

The researcher's judgment is a prominent factor, thus the researcher creates a characteristic criterion selection list which the sampling population has to meet (Strydom, 2005b:214). The selection criteria list for parents as caregivers of adult children living with schizophrenia was as follows:

- Caregivers of adult children (living with schizophrenia) who were attending Mfihlakalo Day Care Centre.
- Caregivers should have been caring for adult children living with schizophrenia for five years or more.
- The adult children living with schizophrenia should have been attending Mfihlakalo Day Care Centre for five years or more.

The criteria were used to ensure that the goal of the study was achievable through aligning them with the topic and objectives of the study, thus exploration of cultural belief systems from parents as a caregivers of adult children living with schizophrenia was a central point. The researcher reached a point of saturation with 12 participants who successfully met the criteria to participate in the study.

3.2.5 Data collection

Greeff (2011:351) stipulates that qualitative data collection methods play an important role, as they provide in-depth information useful to understand processes behind the research results. The researcher needs to record any potential useful data thoroughly, accurately, and systematically, using field notes, sketches, audiotapes, and other suitable means (Rubin & Babbie, 2011:467).

A semi-structured, one-to-one interview is used to gain a detailed picture of a participant's beliefs about or perceptions / account of a particular topic. The researcher and participants gain flexibility in this regard and the participant is able to give a fuller picture of his/her experiences (Rubin & Babbie, 2011:467). The researcher utilised the semi-structured interview to gain more in-depth information about the participants'

perceptions regarding cultural beliefs about schizophrenia. This data collection method was advantageous to both the researcher and participants, as it allowed for flexibility throughout the interview (Neuman, 2006:250). Participants felt at ease and were comfortable in sharing their belief systems. The researcher was also able to be attentive through observation of body language when participants shared their opinions (Greef, 2011:352).

Holstein and Gubrium (in Fouché, 2011:352) define an interview schedule as a questionnaire written to guide the interview. The interview schedule assists the researcher to establish predetermined questions that will engage the participants and designate the narrative terrain. This is advantageous as it gives the researcher an opportunity to think about what she hopes the interview will cover and the difficulties that might be encountered in terms of wording and sensitive areas.

The use of the interview schedule allowed the researcher an opportunity to thoroughly prepare for the interview. It made the interview process easy as it guides the process, reducing unnecessary deviation from specific aspects. Participants were informed that the interview may take a prolonged period due to the richness of the experiences shared. Flexibility in terms of allowing participants to start with questions they feel comfortable with and allowing the discussion to move away from the questions on the interview schedule may elicit factual information (Greef, 2011:353). The participants were able to share additional experiences that were not covered in the interview schedule which enhanced richness of data. The researcher was careful not to harshly cut off participants, but ensured that she redirected them to the core questions with ease through reflection on the question at hand.

The researcher further enhanced the information collection process by making use of a digital recorder and field notes as a method of recording the information. The researcher recorded the interview with the consent of the participants. The researcher explained to the participants that the purpose of the recorder was to ensure that all discussions that could not be captured through field notes would be recorded. The researcher had an

assistant who was helping with the logistics of the interview. Smith (in Greef, 2011:298) mentions that a digital recorder allows for a much fuller record than notes taken during the interview. The researcher is in consensus with the author, as a tape recorder was able to record all the discussions, while allowing the researcher an opportunity to be attentive to the participants as they shared their experiences. The recorder also allowed the researcher an opportunity to listen to the interview after the actual interview session.

The use of semi-structured interviews allowed the researcher an opportunity to collect rich, in-depth data from participants. The questions posed to participants were open-ended, motivating participants to participate. The researcher was in personal contact with the participants, allowing her an opportunity to promote attentiveness such as eye contact and nodding throughout the participant's responses (Bless et al., 2006:425; Greeff, 2011:212; Strydom, 2011b:89; Strydom & Delpont, 2011:46).

3.2.6 Data analysis

Schurink, Fouché and De Vos (2011:36) explain that data analysis is a process of bringing order, structure and meaning to the mass of collected data. The researcher utilised Creswell's model of data analysis, which emphasises that "data analysis is always an on-going process that routinely starts prior to the first interview" (Creswell, 2009:184). The researcher used the following data analysis steps as a guide to analyse collected data:

- **Planning for recording of data**

When planning for the recording of data the researcher needs to ensure that the recording techniques, such as observation and taking notes, do not intrude on the on-going flow of daily events (Welman et al., 2005:112). The researcher gained participants' consent to record the interview, as she did not want to seem insensitive by taking notes throughout the whole interview. The researcher also captured minimal field notes and relied mostly on the tape recording to capture the interview. The researcher coded the notes for better presentation when later writing the final product of the research (Schurink et al., 2011:48).

- **Data collection and preliminary analyses**

The researcher analysed data in the field through observation of non-verbal cues, emerging themes, and being attentive to the change in voice tones when participants were sharing their experiences. Data was also analysed away from the field by means of sorting and indexing the data for better presentation and categorisation (Creswell, 2009:186). The researcher also checked emerging hunches as participants shared information that was not covered in the interview schedule, as mentioned earlier. The researcher used existing data to make sense of the emergent themes (Grubich, in De Vos et al., 2011:405).

- **Managing or organising the data**

The researcher did the first data analysis away from the site by formulating the data into sentences and then saved them as computerised files. The researcher opted for computerised files as they are easily accessible and secure. The researcher typed handwritten field notes and transcribed technical data which was then saved in the computerised files. The computerised files were organised in a folder according to themes (De Vos et al., 2011:408).

- **Reading and writing the memos**

The researcher read the organised and converted data several times until absorption and understanding of the details of the study was achieved. The researcher made use of note taking as it assisted her to jot down important key concepts (Welman et al., 2005:114). The researcher also wrote memos immediately after the beginning of data collection in the margins of the field note pages or transcripts. The researcher made use of theoretical notes as they assisted her in systematically and critically reflecting on deeper meanings of concepts and what took place, including the researcher's own feelings regarding the research study (De Vos et al., 2011:409).

- **Generating categories and coding the data**

The researcher utilised open coding to categorise and name phenomena through breaking down, examining and conceptualising collected data (De Vos et al., 2011:409). The researcher formed themes and patterns by identifying terminologies, concepts and behaviours that were used. The participants were named alphabetically, i.e. Participant A, Participant B, Participant C, and so forth.

- **Testing the emergent understandings**

The researcher evaluated data that emerged which was not part of the study. The importance of the emerged data was evaluated through the use of the research question to check the relevancy of the data. The data was then explored and studied, making links to the study (Creswell, 2009:188).

- **Interpreting and developing typologies**

Interpretation involves making sense of the collected data. The researcher needs to identify the form of interpretation, whether it is based on hunches, intuition or insight (De Vos et al., 2011:416). Developing typologies is a process whereby the researcher makes linkages between different phenomena (Welman et al., 2005:116). The researcher interpreted data by using insight and personal views as gathered from participants. The researcher made linkages between phenomena with common characteristics.

- **Presenting the data**

The researcher made use of themes and sub-themes to disseminate the findings of the collected information. The researcher presented the collected and analysed data in the form of a written mini-dissertation (Gibbs, 2011:25).

3.2.7 Trustworthiness

In an effort to ensure the rigor of the study, the researcher ensured that appropriate research methods were implemented. Trustworthiness is established when findings as closely as possible reflect the meaning as described by the participants (Lietz, Furman & Furman, 2006:444). The researcher established trustworthiness in an attempt to reduce reactivity and biases from the part of both the researcher and participants. In the process of ensuring trustworthiness, the researcher utilised reflexivity and peer debriefing strategies.

Reflexivity is the active acknowledgement by the researcher that his/her own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation (Lietz et al., 2006:447). The researcher is from the same community as the participants, thus she has deemed the use of reflexivity necessary to address her own biases as she has been exposed to some of the cultural beliefs regarding mental illness in the area. The researcher embarked on a journey of self-reflection regarding her beliefs and experiences (Lietz et al., 2006:447), as they intersected with that of the participants. By reflecting on her own belief systems and becoming aware of them, the researcher was able to realign herself with the study and put her biases and beliefs aside. The researcher ensured that she did not allow her own opinions of the phenomenon to overshadow the participants so that they could share their own opinions. The researcher was able to listen to and capture the participants' accounts of cultural beliefs with regard to schizophrenia without making any additions or subtractions from the collected data.

The researcher consulted with other colleagues who provided expertise knowledge on schizophrenia and the African culture through peer debriefing. The researcher's colleagues offered useful points on the topic and allowed the researcher an opportunity to review the information she had, adding any useful information that was left out (Lietz et al., 2006:451). The dialogues with other colleagues allowed them an opportunity to grasp the goal of the study and to make positive contributions that aided the successful achievement of the goal and objectives of the study.

3.3 PILOT STUDY

The researcher tested the interview schedule on two caregivers from different households (Bless & Higson-Smith, 2000:155). This allowed the researcher an opportunity to make improvements on the questions in the interview schedule and to check the technical aspects, such as the sound and positioning of the tape recorder. The participants were aware of the equipment and gave permission for the researcher to use it. The pilot study was advantageous as it made the researcher aware that one recording device would not be plausible due to the big venue that was provided for the study. The researcher then tested two identical recording devices and this produced much clearer and audible recordings. The data proved to be relevant to the study as tested out during pilot session (Royse, 2011:172).

3.4 ETHICAL ASPECTS

The study was conducted in a morally ethical manner, as the researcher gained ethical permission from Mfihlakalo Day Care Centre and the University of Pretoria's Ethics Committee to proceed with the study. The ethical issues are applicable to the study were adhered to as follows:

- **Informed consent**

Bryman (2012:136) emphasises that participants need to be informed about the nature of the study to be conducted and their power to choose whether to partake in the study or not. The researcher informed participants about the goal, objectives, procedures, advantages, disadvantages and dangers of the study before the interview so that they could make an informed decision whether to participate in the study or not. The researcher emphasised to the participants that the study is for academic purposes with no monetary incentives for herself or participants. The researcher ensured that participants understood the contents of

the informed consent form by translating it into Setswana for those that struggled with the English template.

Only participants who signed the consent form to grant the researcher permission to interview them and partake within the study were allowed to participate in the study. The signing of consent forms was a way of indicating that participants understood the nature of the study and the risks thereof (Babbie, 2007:24). The researcher also received permission from the participants to use a tape recorder to record the interview. The researcher explained to participants that the digital recording is used solely for purposes of capturing information that might be left out by the researcher during the interview. The recorder was also explained as useful, as it will later be used during data analysis.

The participants were informed that their identity will be kept confidential as the researcher made use of alphabetic domains to refer to participants. The researcher further informed the participants that the data will be securely kept in the Department of Social Work and Criminology at the University of Pretoria for a period of 15 years.

- **Avoidance of harm**

The researcher was aware that the study might evoke emotional experiences for participants, thus participants were warned of any possible emotional pain that might result from the interview, as it could be of a personal nature (Babbie, 2007:27). Participants were informed that those who might be affected emotionally would be referred to a psychologist or social worker at the local clinic. There was no need for referrals to the psychologist or social worker after the interview as there were no participants that needed any counselling interventions.

After the interview, the researcher had an opportunity to answer any general questions that the participants had, as the process was a learning experience both for the participants and the researcher.

- **Deception of subjects**

The researcher provided participants with all the information they needed about the study. Participants were allowed to sign the consent form only after understanding the contents of the consent form. The researcher refrained from withholding any information from participants, but rather shared everything the participants needed to know with regard to the study (Babbie, 2007:474). The researcher translated the information into Setswana to ensure complete understanding of the nature of the study for participants.

- **Violation of privacy/anonymity/confidentiality**

The researcher made use of the alphabet to name participants in order to maintain privacy, i.e. Participant A, Participant B, etc. The researcher maintained confidentiality by not disclosing the research information outside of the research study. Participants were informed that the final results and package of the study will be made public in the form of an academic mini-dissertation.

- **Actions and competence of researcher**

Babbie (2007:476) indicates that researchers have to be ethically competent, honest and adequately skilled to do research and acknowledge sources in their studies. The researcher informed the participants that she is in possession of a Bachelor's degree in the field of social work which equipped her with the theoretical and practical knowledge to conduct research. The researcher also pointed out that she was granted permission to conduct the study by the Ethical Clearance Committee of the University of Pretoria and Mfihlakalo Day Care Centre. The researcher treated participants with respect and dignity. Participants' right of self-determination was also not violated as participants made informed decisions to participate in the study without any coercion.

In terms of the documentation of the research results, the researcher acknowledged sources of literature and interviews that were consulted

throughout the study to avoid plagiarism. Information will also be portrayed as collected from and reflected by participants. The researcher will also treat participants with respect and dignity.

- **Debriefing**

Strydom (2005a:66) states that debriefing allows participants to work through their experiences after the interview. The researcher had prepared for any need of debriefing although it turned out to be unnecessary, as there were no participants that needed any means of counselling during or after the interview.

- **Release or publication of findings**

The researcher informed the participants that the research results would be released in the form of a mini-dissertation that will be made public at the University of Pretoria's library (Babbie, 2007:476). The participants were also informed that the Mfihlakalo Day Care Centre will also receive a copy of the mini-dissertation for their own library.

SECTION B: EMPIRICAL STUDY

In this section, the research findings will be presented and discussed in detail. The first section will focus on the biographical data of participants, followed by the presentation and discussion of themes and sub-themes as they emerged from the data. The data was collected from interviews with 12 participants; therefore data from 12 participants will be presented and substantiated by direct quoted responses from participants.

3.5 BIOGRAPHICAL DATA

The study was focused on parents as caregivers of adult children living with schizophrenia. The participant's biographical data includes the following factors:

- Age of participants
- Gender of participants

- Marital status
- Language
- Sources of income
- Number of dependants
- Age distribution of dependants
- Day care centre attendance at Mfihlakalo Day Care Centre
- Years of parents' care giving experience

3.5.1 Age of participants

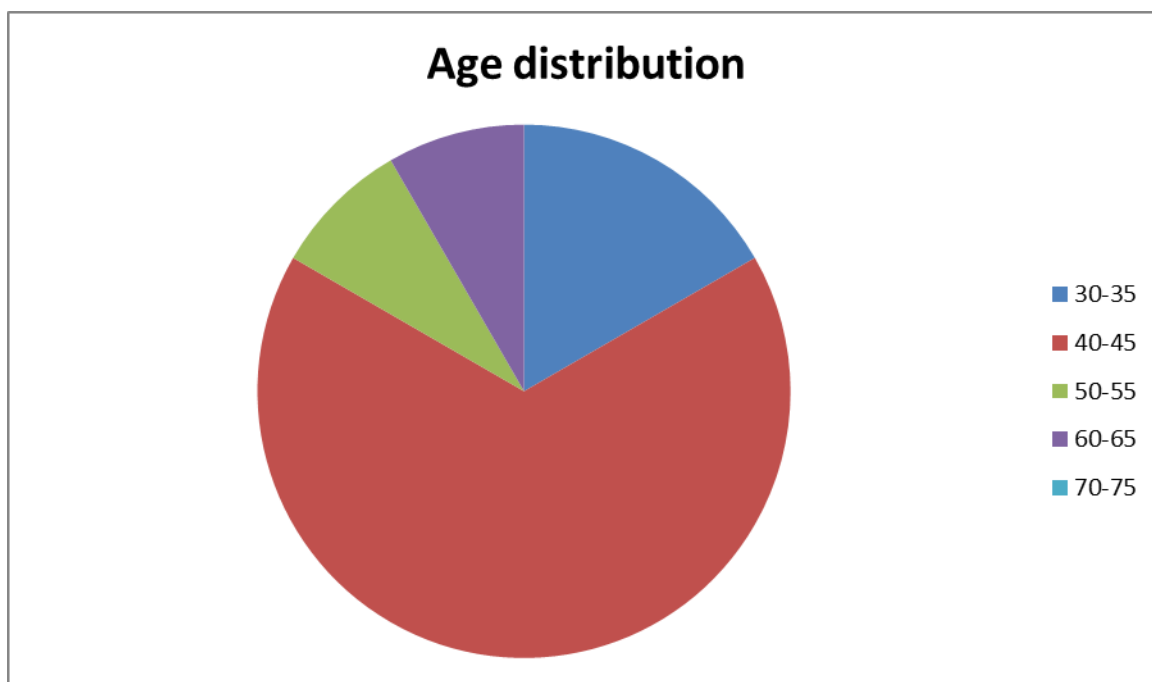


Figure 3.1: Age distribution of participants

In Figure 3.1, the pie chart represents the age distribution of participants. The sum of the whole pie chart represents the aggregate age ranges of participants. The researcher interviewed 12 black African participants. Two of the participants were between the ages of 30 and 35; eight participants were between the ages of 40 and 45; one participant was between the ages of 50 and 55; and another participant was between the ages of 60 and 65. There were no participants between the ages of 70 and 75.

3.5.2 Gender of participants

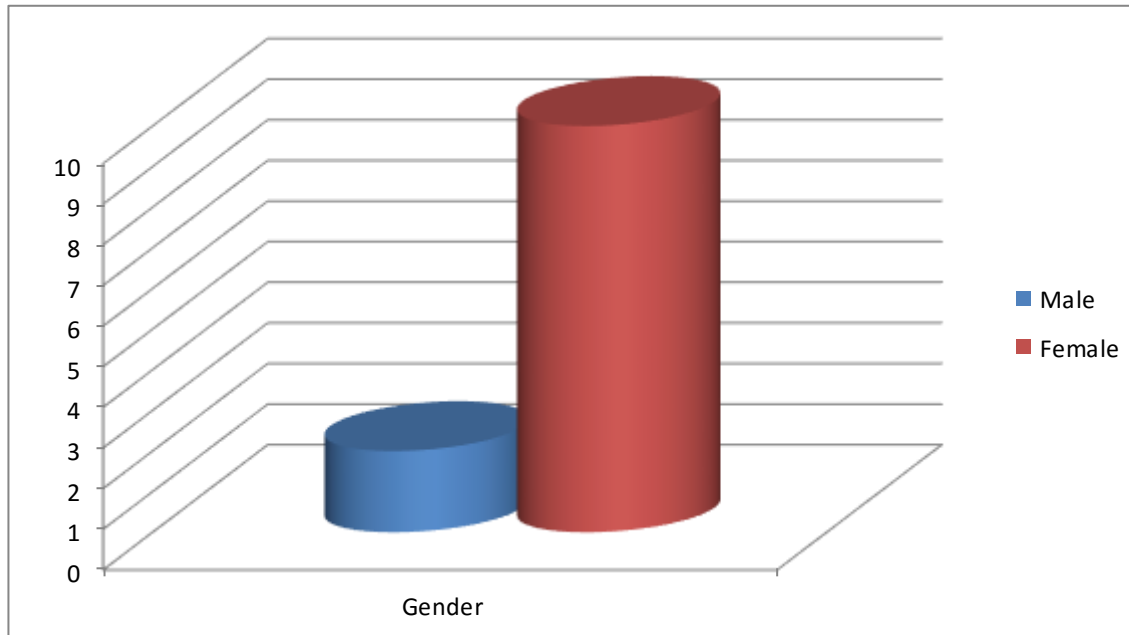


Figure 3.2: Gender of participants

Figure 3.2 above indicates that there were ten female participants and two male participants, coming to a total of 12 participants in the study.

3.5.3 Marital status of participants

Figure 3.3 below indicates that two of the participants were single and never married before; four participants were married and living with their partners; one participant was widowed; five participants were not married, but living with partners; and there were no divorced participants.

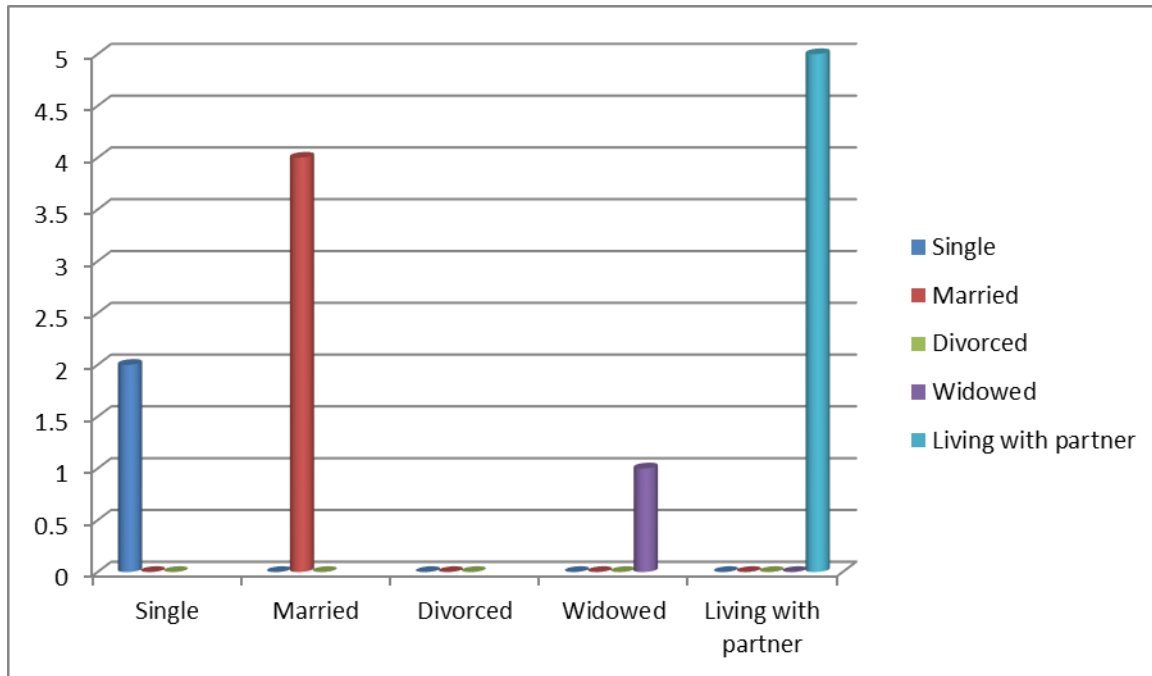


Figure 3.3: Marital status of participants

3.5.4 Language of participants

Table 3.1: Language of participants

Language	Participants
Setswana	12
Sepedi	0
Sesotho	0
Isizulu	0
Xitsonga	0
Tshivenda	0
Total	12

Table 3.1 above is a representation of the participants' home languages. The results shows that all 12 participants were Setswana speaking. The participants indicated that they understand English. The interpretation in Setswana was utilised throughout the study for better understanding.

3.5.5 Age distribution of dependants

Table 3.2: Age distribution of dependants

Age distribution of dependants	
19-25 years	9
26-35 years	3
36 years and above	0
Total	12

Table 3.2 is a representation of ages of dependants under the care of the participants. The results show that nine participants were caring for dependants between the ages of 19 and 25 years, and three participants were caring for dependants between the ages of 26 and 35 years. There were no participants caring for dependants aged 36 years or older.

3.5.6 Sources of income

Ten participants reported that they were recipients of the social disability grant. One participant was employed, another participant was receiving income from a partner, and none of the participants were self-employed.

3.5.7 Number of dependants cared for by participants

Two participants reported that they were caring for one or two dependants; eight participants were caring for three to four dependants; and two participants were caring for five to six dependants.

3.5.8 Attendance at Mfihlakalo Day Care Centre

All the 12 participants indicated that their adult children living with schizophrenia were attending day care at Mfihlakalo Day Care Centre for two years or more.

3.5.9 Years of parents' care giving experience

Table 3.3: Number of years caring for adult child(ren) living with schizophrenia

Number of years caring for adult child(ren) living with schizophrenia	Number of participants
5 years	04
6 years	06
7 years	0
8 years and beyond	02
Total	12

The results in Table 3.3 indicate that four participants were caring for their loved ones for five years; six participants were caring for their loved ones for six years; and the remaining two participants had been caring for their loved ones for eight years or more.

3.6 EMPIRICAL FINDINGS

Themes and sub-themes emerged from the recurring data. The following table is a presentation of the recurring themes and sub-themes:

Theme	Sub-theme
Theme 1 Understanding of schizophrenia	1.1 Knowledge of schizophrenia 1.2 Diagnosis of schizophrenia
Theme 2 The causes of schizophrenia	2.1 The Caregiver's perception of causal factors of Schizophrenia 2.1.1 Genetic factors 2.1.2 Physiological factors 2.1.3 Psychological factors 2.1.4 Environmental factors 2.1.5 Cultural factors

Theme 3 Symptoms of schizophrenia	3.1 Positive and negative symptoms of schizophrenia
Theme 4 Challenges experienced by parents as caregivers in caring for adult children living with schizophrenia	4.1 Lack of understanding of the illness 4.2 Behavioural patterns of dependants
Theme 5 Programmes for mental health care users	5.1 Vocational programmes for mental health care users 5.2 Exit plan for mental health care users

3.6.1 Theme 1: Understanding of schizophrenia

The participants' responses showed an indication of lack of contextual understanding of schizophrenia. The knowledge of schizophrenia and professional diagnosis of schizophrenia emerged as sub-themes.

3.6.1.1 Sub-theme 1.1: Knowledge about schizophrenia

The findings showed that participants did not have adequate knowledge about the context of schizophrenia. The majority of participants' knowledge about schizophrenia was minimal and lacked context as proven by the following expressed statements:

- *Participant A "...it is a natural illness."*
- *Participant B "...eh,,from what I heard it is an illness that is transferrable from a parent to child. "*
- *Participant C "...it is a natural illness."*
- *Participant D "...Yes,, natural illness."*
- *Participant E "...it is a natural illness."*
- *Participant F "... natural illness."*
- *Participant G "...it is a natural illness."*
- *Participant H "... natural illness."*

- *Participant I “...it is a mental illness.”*
- *Participant J“...it is a mental illness.*

Schizophrenia is a spectrum of disorders with complex manifestations ranging between cognitive, behavioural and emotional dysfunctions or abnormalities (APA, 2015). The Mental Health Care Act (1997) defines mental illness generally as a positive diagnosis of a mental health related illness in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to make such a diagnosis. Burke (2012:200) expands on the definition by adding more contexts to the term and classifies it as a psychosocial or cognitive impairment resulting from genetic, physiological, social or psychological malfunctioning or disturbances. The latter definition provides a more concise understanding of mental illness. There are different types and classifications of mental illness which include schizophrenia, mood disorders, personality disorders, eating disorders, and many more.

The participants’ expression of schizophrenia as a mental illness is supported by the Diagnostic and Statistical Manual of Mental Disorders (APA, 2015) which states that schizophrenia is a severe type of mental illness that constitutes a disturbance that lasts for at least six months, of which one month is an active phase of symptoms such as hallucinations and delusions. In accordance with the APA (2015), Barlow and Durand (2009:467) reaffirm that schizophrenia is a form of mental illness characterised by a broad spectrum of cognitive and emotional dysfunctions, including delusions, hallucinations, disorganised speech, and inappropriate emotions.

Schizophrenia is notably a disorder that causes dysfunctions not only in the lives of those living with the disorder, but also for those affected by the disorder. The inability to respond positively to the natural demands of everyday life poses a significant challenge in these individuals’ lives, as drastic changes such as role changes, financial stability and caring options have to be reconsidered. The researcher further believes that the more knowledgeable people are about the disorder, the better the chances of effective management and treatment of the disorder.

Although people do not often consider factual knowledge, but rather their own personal belief systems when explaining health behaviour, the Health Belief Model emphasises the importance of knowledge about specific conditions in order to know how to deal with them (Jones & Bartlett, 2004). Aligned with the Health Belief Model, Anderson and Adams (1996:505) assert that mental health care users and their families need to be empowered with knowledge about mental illnesses as this will improve the management and control of disorders. The Health Belief Model indicates that people tend to seek positive and healthier behaviours to avoid the negative implications of acquiring a specific condition; and this is considered only when adequate knowledge about the perceived threat is accessed.

It can therefore not be stressed any more that imparting knowledge and an awareness of schizophrenia to mental health care users and their families is important. When making a diagnosis, the researcher believes that health care professionals play an important role in ensuring that people are aware of schizophrenia and how to handle it. Social workers can expand on this through group and community educational programmes on mental illnesses, especially schizophrenia.

3.6.1.2 Sub-theme 1.2: Diagnosis of schizophrenia

Eight participants reported that their adult children were diagnosed by psychologists, while four participants indicated that the diagnosis was ruled out by medical doctors.

Although some of the participants did not know the specialisation of the doctors that diagnosed their children, it was clarified that the doctors were qualified medical practitioners working in recognised hospitals. The responses supporting the above information were as follows:

- *Participant B “Mine is Dr Chauke, he works at Odi Hospital.”*
- *Participant C “Myself, mine is Dr Kgapa.”*
- *Participant D “...he is a psychologist.”*

- *Participant E “... a psychologist.”*
- *Participant F “... psychologist.”*
- *Participant G “...also psychologist.”*
- *Participant H “...he is a psychologist.”*
- *Participant I “...he is a psychologist.”*
- *Participant J “...also psychologist.”*

The diagnoses of schizophrenia for adult children cared for by the participants are considered authentic as they were endorsed by qualified health professionals. This is supported by the Mental Health Care Bill (2000), which asserts that a mental illness should be diagnosed by a mental health practitioner in terms of accepted diagnostic criteria. Videbeck (2009:271) is in consensus with the Mental Health Care Bill that qualified health practitioners such as psychologists and psychiatrists can make a diagnosis in terms of mental illnesses. These professionals work in partnership with mental health nurses and medical doctors.

The researcher ponders on the notion that the complexity of mental illness makes it challenging for health practitioners to make accurate diagnosis without considering other factors such as childhood development, culture and medical history. It is for this purpose that a set strategy for diagnosis has been implemented which is the Diagnostic Statistical Manual of Mental Disorders. Barlow and Durand (2009:467) indicate that diagnosis of schizophrenia is ruled out by a qualified health care professional following the guidelines of the Diagnostic Statistics Manual. The Diagnostic Statistics Manual of Mental Disorders is a diagnostic tool that assists clinicians to make an accurate diagnosis. The manual is advanced over time to continuously include current trends in mental health (APA, 2013). The researcher agrees with the statement as she realised that the DSM 5 incorporates cultural considerations during diagnosis. In the researcher’s view, this will ensure that cultural aspects are considered when making a diagnosis which in itself might yield better diagnosis, treatment and recovery results.

The Health Belief Model emphasises that health-related behaviour is determined by personal beliefs or perceptions about a disease, thus leading to different approaches to reduce the incidence of the disease (Jones & Bartlett, 2004). Because of the complexity of schizophrenia, all aspects of the disorder need to be explored. It is therefore important to note that the Diagnostic and Statistical Manual of Mental Disorders is deemed appropriate for accurate diagnosis of mental disorders, as it is continuously reviewed and advanced, with specific focus on inclusion of the latest cultural, social, environmental and psychological factors influencing manifestation of the disorders. The diagnostic tool therefore aligns with the constructs of the Health Belief Model of personal belief systems influencing health behaviour. Exploration of such factors thus improves the level of understanding of schizophrenia from the parents' cultural point of view as caregivers.

3.6.2 Theme 2: The causes of Schizophrenia

The most common perceptions of the causes of schizophrenia as stated by participants included genetic, physiological, psychological, environmental, and of course cultural factors. The sub-themes that emerged are discussed below.

3.6.2.1 Sub-theme 2.1: The Caregiver's perception of causal factors of Schizophrenia

- **Genetic factors**

The majority of participants' responses credited the biological factors as having influenced the development and manifestation of schizophrenia in their adult children. The following are expressed statements from the participants as supported by genetic factors of schizophrenia:

- *Participant E "...eh...from parents..."*
- *Participant C "I, they explained that the child got the illness from his mother too."*

- Participant B “... [eh] from what I heard it is an illness that is transferrable from a parent to a child.”

The statements above replicate Burke (2012:220) who states that schizophrenia is a mental disorder described through multiple biological elucidations. Burke (2012:220) reiterates that inherited gene vulnerability plays a role in developing the disorder whereby people who have family members living with schizophrenia have vulnerability to develop the disorder. The vulnerability increases with the generational degree of relativity with such family members. Those who have biological parents with the disorder along with identical twins have the highest vulnerability (Kaplan, 2002:454).

Offspring born from parents living with schizophrenia are reported to have 6% probability of inheriting the disorder (Selwood, 2012:212), while monozygotic twins are argued to have a 50% probability of developing the disorder as they share 100% of each other’s genetic material (Videbeck, 2009:272:86). Culturally, belief systems attached to disease include amongst others the belief that diseases are passed down from one generation to the next within a specific blood line (Ngong, 2000:56). This increases susceptibility to disorders and motivates individuals to seek positive health behaviours in order to avoid consequential circumstances following the acquisition of a specific disorder (Brieger, 2006:54).

From the above statements, the researcher believes that schizophrenia is a generational disorder that affects people who have family members with a history of the disorder. It can also be argued that the disorder is prevalent among those with shared genes. It is therefore crucial for personal belief systems to be taken into consideration when addressing health challenges, as these belief systems provide clarity on health behaviours. Furthermore, the susceptibility theory of the Health Belief Model (Jones & Bartlett, 2004:28) supports the vulnerability theory of the biological contributions to schizophrenia which both argue that the existence of a disorder within a family line increases the belief of surviving family members’ predisposition to that specific disorder.

The findings of the study provide concrete evidence for existence of an array of biological factors that influence the development and manifestation of schizophrenia. Health care professionals are mainly relying on biological factors to explain the existence of schizophrenia. The use of biological explanations for schizophrenia motivates medical treatment options for the disorder with an attempt to reverse the process or rather to reduce or control the physiological defects. Careful and additional studies on biological theories of schizophrenia are still crucial to substantiate current theories, with the reemphasis on the focus of personal belief systems as explanatory factors for health behaviours as stated by the Health Belief Model (Brieger, 2006:54).

- **Physiological factors**

Two of the participants added physiological causes of schizophrenia, mainly relating to head injuries and complications during pregnancy. Participants described these situations as follows:

- Participant D “*eh it caused by maybe... I have an operation on my head. And the first child was not alright... and the second one too was not alright.*”
- Participant H “*when I was pregnant I fell...*”

Complications during pregnancy have been reported to have a strong link to schizophrenia. Complications such as head injuries, poor nutrition, exposure to viral infections, and strenuous exercise were reported to have been linked to numerous cases of schizophrenia (Videbeck, 2009:42). Although there is not enough evidence in terms of the extent of consequences of such complications, it can arguably be noted that severe harm to the foetus or viral infections can cause defects that might contribute in the development of schizophrenia. Personal belief systems about a health condition influences specific health behaviours (Brieger, 2006:51). It can equally be argued that the complications during pregnancy increase the susceptibility of schizophrenia to an unborn child as believed by parents. The Health Belief Model expands further on this point by indicating that the beliefs about consequences of a health problem are aligned to personal belief systems attached to that specific condition (Brieger, 2006:51). Consequently the beliefs about schizophrenia being caused by complications during

pregnancy are firmly held assumptions by the respondents, influenced by their personal belief systems.

▪ **Psychological factors**

Participants perceived stress as a causal factor of schizophrenia. Participants explained it as follows:

- *Participant G “stress, thinking too much, when you think of this, that thing stays in your mind...”*
- *Participant E “mine was always sitting alone in his room, he was always alone and did not want with his things.”*
- *Participant B “playing, you find that when others are playing, he looks with awe....when you ask him why do you look like that, he says”aowa I dnt know”*

The above statements are supported by Burke (2012:213) who indicates that stressful life events have been linked to the development of schizophrenia. Life events such as traumatic experiences can cause neurological impairments that can later manifest into schizophrenia. Stress is an excessive worry about specific events without a proper solution; such worry can result in a hormonal imbalance, which then affects the psychological functioning of individuals (Burke, 2012:213). Furthermore, the stress can also manifest itself in different ways whereby individuals would isolate themselves or get easily agitated.

The Health Belief Model stipulates that explanations for health behaviour can arguably be linked to personal belief systems as held by individuals. These belief systems are influenced by cultural, social, and environmental factors surrounding the individual. Notably so, stress as a causal factor of schizophrenia is influenced by belief systems held by individuals in explaining health behaviour (Taylor et al., 2007:211).

- **Environmental factors**

Participants had the view that alcohol consumption during pregnancy plays a major role in the development and manifestation of schizophrenia. Participants discussed this as follows:

- Participant B “...*When the woman is pregnant, like, you see... if she drinks, ja and she is not taking care of the pregnancy... that also causes the illness...*”
- Participant F “...*Not taking care of the baby when one is pregnant*”
- Participant H “...*yes...when I was pregnant I fell...*”

The above statement is confirmed by Selwood (2012:26) who asserts that obstetric complications and influences such as exposure to infections, sexually transmitted diseases, maternal stress, and use and abuse of alcohol and other substances during pregnancy cause and increase susceptibility to the development of schizophrenia. Picchioni and Murray (2007) indicate that obstetric complications such as premature birth, low birth weight, and perinatal hypoxia are additional contributors of vulnerability to developing schizophrenia. Townsend (2005:274) further argues that most individuals are from poverty-stricken communities living below poverty lines, where they do not have the means to care for themselves properly or even to implement effective coping mechanisms. This results in malnutrition, inadequate prenatal and antenatal care, and lack of proper health care services.

The researcher believes that the development of healthy babies depends on the proper care, nutrition and wellbeing of the pregnant mother. Challenges in these areas are believed to play a major role in causing adverse health challenges not only for the mother, but also for the unborn child. Such belief systems can be influenced by specific cultural or social factors (Brieger, 2006:52). Effects of substances on an unborn baby can cause major neurological disorders, developmental challenges and ill health (Burke, 2012:202). The Health Belief Model also states that the beliefs about consequences of a health problem are aligned to personal belief systems attached to that specific condition (Brieger, 2006:51)

▪ Cultural factors

The majority of the participants perceived cultural factors as playing a prominent role in the development and manifestation of schizophrenia. Nine participants stated that cultural belief systems influence the development of schizophrenia. The participants emphasised it as follows:

- Participant G *“stress, thinking too much, when you think of this, that thing stays in your mind, you think of it that, that think comes again, nothing goes well in your life, by the time you accept....it God’s things right, you do things, that does not make sense, that you can never see, you think of it,you see things you haven’t seen before, everything is created by God,right.
...it is a belief, it’s things that are done by a person’s belief. Everything is generated by a person’s mind and belief...When you believe it will work for you, people will ask how did you get him right.”*
- Participant K *...when a child is like this, it is because they grew up this way, he is not normal”*
- Participant I *“there is a problem that when a child is born from the flesh then there’s things that happen, its witchcraft”*
- Participant E *“believe in witchcraft. A child is this, ancestors said this...even you,,,parents believing it is witchcraft, and these children were hidden, even at home and the family (other participants mumbling in agreement) if you see the child, all they would behave odd, whoof whoof, myeeh myeeh (dog and goat sounds), you would see that this child was spending time with animals there is no one who takes care of him, and others when they eat, they would eat eggs with their shells, this child when he eats, he eats like a dog, when you put a plate next to him, he takes the head and mxa mxa mxa (gesture and sound of dog eating)”*

- Participant B – *“eh, I want..., my child challenging, but I want u to knw, school is important. I started him with crèche, u knw a child that has problems, I accepted, started taking him to crèche, to crèche, now he is here, he has everything but, u find that... on the other side I am trying. Then it started again, you will find that when a person comes along like this, he would run and grab the person like this (signaling a hug) then he fall unconscious. We heard from people and had never seen it ourselves before, we started seeing. He was very disrespectful and hammered on things, he liked to (claps hands) then he would do his work, then he would be angry with you”*

The participant’s response correlates with the argument by Labuschagne et al. (2003:109) that cultural beliefs shape social interactions, thus leading to specific perceptions about different aspects. Environments that people grow up in shape their perceptions about reality. The belief systems held by people determine how they react to specific events. As indicated by the participant, the faith in a belief system encourages the ability of the belief system to yield results. It has been noted that any African cultural belief system works according to the degree of faith that a person has in that belief system (Makau, 2003:08). The strong forces behind the belief system release powers for healing, removing curses, or even reincarnation of spirits. Traditional healers also emphasise the need to believe in whatever instructions are given to patients, as without belief the instructions will not yield the expected results (Makau, 2003:08).

Additionally, because the Health Belief Model emphasises an argument that health-related behaviour is influenced by personal belief systems, the latter also applies to health care professionals to make extra efforts to be knowledgeable about different cultural belief systems so as to improve service rendering to such clients (Jong, 2003:34). It would therefore serve as an advantage for health care professionals as they would explore all factors in determining a diagnosis.

Furthermore, the 12 participants mutually perceived witchcraft and practices related to ancestors as also being prominent causes of schizophrenia. These perceptions are supported by the following responses from three participants which the rest of the participants were in consensus with:

- *Participant E “believe in witchcraft. A child is this, ancestors said this...even you,,,parents believing it is witchcraft...”*
- *Participant F“...they talked about witchcraft... the child’s paternal aunt puts a curse on the child...”*
- *Participant K ...when a child is like this, it is because they grew up this way, he is not normal”*

Stevenson (Makau, 2003:12) asserts that cultural beliefs carry explanatory value of human personality and biology which current theories cannot adequately clarify. This explains the reasoning behind cultural events being responsible for biological factors such as diseases. Diseases are further explained as caused through supernatural forces or even foreign substances in the body. Persecution is another cultural factor linked to the development of mental illness (McInnis & Merajver, 2011:168).

The belief of diseases being attributed to cultural factors definitely motivates traditional consultation processes in terms of treatment for diseases. The researcher is of the opinion that it would only make sense for Africans to consult a traditional healer who would be regarded as more knowledgeable in terms of understanding and interpreting cultural signs and symptoms of disease, rather than Western health practitioners who are regarded as lacking cultural awareness. Mosotho et al. (2008:171) add that Africans consult traditional healers because family members encourage them to do so, as it is family tradition and also because traditional healers carry supernatural gifts that enable them to communicate with ancestors. In some cases Africans opt for dual consultations whereby the traditional healer will be consulted for supernatural causes and explanations and the Western doctor is consulted for symptomatic relief (Ellis, 2004:108)

Makau (2003:09) asserts that indeed Africans believe that mental illness is caused by curses, witchcraft and elements of jealousy. In African communities, the paternal aunt is believed to possess the powers to determine a child's future. This belief system indicates that when the paternal aunt is angry she can put a curse on the child. This curse can only be reversed by the same aunt through an ancestral ceremony where she will recite traditional rites of passage for the child and give him/her an ancestral/clan name (Ngong, 2000:52).

The researcher denotes that culture is held as a sacred ideation to Africans, thus the belief systems attached to culture are significant to them. The exposure to such cultural connotations is reality to Africans as it is the only truth known to them, hence it is evident that the reasoning of diseases as relating to cultural factors is of high significance to them. Of course the researcher notes that what might be regarded as reality in one cultural setting might be different in another, hence it is arguable that the need for cultural sensitivity is of the utmost importance. This will ensure that no specific cultural belief will be held in higher regard than another.

There is invariably a connection between the cultural explanations of schizophrenia and the Western explanations of schizophrenia. This shows that there is an extremely good chance of an individual presenting with cultural symptoms of witchcraft to be diagnosed with schizophrenia in a Western context, as both contexts share similar symptoms (Labuschagne et al., 2003:109). The question now rests in the final diagnosis of whether the presenting symptoms are indeed schizophrenia or just mere spiritual manifestations. Of course this would be answered by the notion of cultural sensitivity as mentioned before; dual use of Western and cultural considerations during the diagnosis process will yield better specifications. Expansion of cultural sensitivity will mediate for the need for health professionals to be trained on cultural aspects of diseases on a preventative rather than curative aspect to address the health challenges within multi-cultural and multi-disciplinary facets as recognised in the White Paper for Social Welfare Services (RSA, 1997a).

Jones and Bartlett (2004:22) point out that the Health Belief Model states that the person's susceptibility to schizophrenia motivates the individual to seek positive health behaviours. This may lead to more positive outcomes of being able to avoid the manifestation of schizophrenia or, in cases where the disorder is already diagnosed, better management and control of the disorder. However, this depends on an accurate diagnosis by a health care professional. The health care professional should be able to rule out the symptoms with consideration of an individual's personal cultural belief systems.

The study indicates that the Health Belief Model promotes positive health behaviour through its distinctive predictive nature (Brieger, 2006:48). The study supports that parents as caregivers of adult children living with schizophrenia might encounter challenges in ensuring adherence to medication by their adult children based on numerous factors (Jones & Bartlett, 2004). Firstly, the cultural belief system attached to medical treatment of the disorder, secondly the desire to follow orders as set out by consulted traditional healers (Labuschagne et al., 2003:108) and, lastly, the level of effective reduction of symptoms by the medication or consultation process.

Some studies conducted in Africa indicate that folk belief systems, negative cultural belief systems, and stigma attached to schizophrenia are identified barriers to health-seeking behaviour. Labuschagne et al. (2003:112) state that the misconceptions and fears about the disease are supported by long-standing beliefs, such as spiritual beliefs and culturally insensitive rituals. These barriers are belief systems that need to be challenged in order to promote positive health-seeking behaviours. Further research (Makau, 2003:44) shows that there is a mistaken belief that if a family has someone living with schizophrenia, the family is cursed. The Health Belief Model indicates that such perceptions are continuous barriers to taking positive action (Brieger, 2006:56). It is therefore imperative that such belief systems be explored further.

The Health Belief Model contributes positively to the restructuring of health services as it provides an understanding of health-behaviour from a personal belief system point of

view (Taylor et al., 2007). The model further suggest that adopting a cultural approach means that any population's cultural references and resources will be considered as key references in building a framework for strategies and project planning. This will in turn promote effective and culturally sensitive programmes and projects in relation to schizophrenia (Taylor et al., 2007).

3.6.3 Theme 3: Symptoms of schizophrenia

Difficulties in speech and unusual behaviour emerged as sub-themes of schizophrenia under the category of positive and negative symptoms of schizophrenia.

3.6.3.1 Sub-theme 3.1: Positive and negative symptoms of schizophrenia

The majority of the participants were of the opinion that the symptoms of schizophrenia as presented by their adult children included difficulties in speech and unusual behaviour. Participants described these behaviours as follows:

- Participant A “...it is difficult as she cannot speak properly also...”
- Participant B “...when she has to say [r] she says [l].”
- Participant C “...sometimes laughs alone...”
- Participant G “...was slow to walk... and talk”
- Participant H “...You know a child that has problems...”
- Participant B “... he was very disrespectful and hammered on things...he liked to (claps hands) then he would do his work, then he would be angry with you...”

Disorganised speech is one of the main symptoms of schizophrenia, whereby it is difficult to make sense of what they are saying when they communicate due to these individuals making a lot of unrelated statements in one sentence or irregularly moving from one point to the next. Burke (2012:206) confirms this statement and asserts that people living with schizophrenia have a verbal communication that does not conform to linguistic rules. The mispronunciation of words or the creation of new words that have never been heard before also pose as a challenge (Barlow & Durand, 2009:467).

Individuals are often observed to be responding to absent stimuli, such as laughing where there is no joke or talking to invisible characters. Barlow and Durand (2009:467) give clarity on this notion and explain it as hallucinations, which are sensory events without any input from the surrounding environment. Hallucinations present themselves in the form of visions or objects unseen by others.

Negative symptoms present themselves as difficulties in motor functions. The above statements indicate inappropriate motor behaviours in terms of delays in walking and fidgety behaviour, such as constant clapping and hammering on objects. This statement is supported by Barlow and Durand (2009:473) who describe negative symptoms of schizophrenia as erratic behaviours that affect speech, motor behaviour, and emotional reactions. Irregular emotional shifts from being happy to being angry are also negative symptoms. The individuals are constantly shifting between moods, making them unpredictable, resulting in caregivers not knowing how to handle them (Labuschagne et al., 2003:108).

The findings of the study show a significant existence of both positive and negative symptoms of schizophrenia among participants' adult children. The symptoms manifest themselves in different forms from one participant to the other. The rationale of the findings indicate that indeed participants' adult children are living with schizophrenia as per provided symptomatic signs. It is crucial to note that participants might interpret symptoms differently in terms of presentation, cultural influence, and media portrayals (Selwood, 2012). Caregivers play a crucial part during consultations, because they are the main sources of information to health professionals and their observations are taken into account in terms of making a diagnosis. Selwood (2012) warns that proper observation of six to 12 weeks should be considered to monitor the behaviour of patients, as caregivers can sometimes be biased or exaggerate the symptoms due to pressure in caring responsibilities.

The Health Belief Model emphasises that individual personal belief systems determine the interpretation of the symptoms of schizophrenia by parents as caregivers of adult

children living with schizophrenia (Brieger, 2006:48). Symptoms of the disease can further be perceived as a motivating factor for taking action about the disease. As mentioned earlier, past experiences of a condition coupled with the degree of severity of the symptoms within a family setting will determine the level of susceptibility and seriousness within that specific family (Taylor et al., 2007:22). The degree of symptoms will further encourage action taking as individuals seek comfort and ease of burden from such symptoms (Brieger, 2006:52).

3.6.4 Theme 4: Challenges experienced by caregivers in caring for adult children living schizophrenia

Lack of knowledge about the disorder and behavioural patterns of dependants emerged as a sub-themes during the study.

3.6.4.1 Sub-theme 4.1: Lack of understanding of the illness

The participants could not provide a concise explanation of schizophrenia, as not enough information was provided to them by health professionals during the diagnosis process. The following statements explain the lack of knowledge regarding schizophrenia as a disorder:

- *Participant A “...I was told that he is a slow learner.”*
- *Participant K “They said mental illness.”*
- *Participant B “I was told he has a disorder for falling and being unconscious, mental illness...”*
- *Participant G “...he is abnormal...”*

Health care professionals are reported as sometimes inconsiderate and not taking enough time to explain disorders to patients. They also reportedly lack cultural sensitivity. Pilgrim (2009:180) urges that the lack of knowledge by caregivers should be an indication or rather invitation for them to pay close attention to the particular meanings being expressed by an individual patient, putting their cultural beliefs in context.

The researcher is of the opinion that because of the complexity of schizophrenia, it is difficult to understand schizophrenia, even for health professionals themselves. It is therefore of utmost importance that caregivers and patients should be allowed ample time to have the disorder explained to them in terminologies more understandable to them. Medical terminologies are not understandable for laypeople who do not have a medical background, thus explanations of the disorder and educational practices should be considered. This is supported by Burke (2012:108) who emphasises that the complexity of schizophrenia makes it difficult for individuals to fully understand it. The White Paper for Social Welfare (RSA, 1997a) emphasises the need for families and communities to be consulted and educated on health programmes. This includes psycho-education about mental illness and how to access services and resources.

As noted earlier, the Health Belief Model encourages understanding of disorders as this promotes positive health seeking behaviours. This is because individuals rely mostly on personal belief systems in terms of explaining health behaviours; hence the need to know and understand health behaviours increases the likelihood of positive health seeking behaviour (Brieger, 2006:52).

3.6.4.2 Sub-theme 4.2: Behavioural patterns of dependants

Most participants stated that their adult children living with schizophrenia present with unusual behavioural patterns, as explained below:

- *Participant B “...he was very disrespectful and hammered on things...”*
- *“...he liked to (claps hands) then he would do his work, then he would be angry with you...”*
- *Participant G“...he would run and grab the person and then fall unconscious...”*
- *Participant I“...quarrels aggressively... he is also not normal.”*

- Participant E“...*would behave in an odd state...and others when they eat, they would eat eggs with their shells, this child. “...would behave odd, whoof whoof, myeeh myeeh [dog and goat sounds]...”*
- Participant B“...*mine was always sitting alone in his room, he was always alone and did not want with his things... when he eats, he eats like a dog. “...he looks with awe... when you ask him why do you look like that, he say [aowa] I don’t know.”*

People living with schizophrenia often present with erratic and illogical behaviours (Barlow & Durand, 2009:473). Selwood (2012:218) indicates that people living with schizophrenia behave differently and there is no one pattern of behaviour that can be attributed to a general population. The statements above show evidence of disrespect, abnormal behaviour, disorientation, and mood shifts. These are some of the attributed behaviours of people living with schizophrenia, but it is of high importance to highlight the fact that not all individuals behave in the same manner (Picchioni & Murray, 2007).

There are numerous factors that influence such behaviours, such as negative attitudes from community members, name calling, regarding them as abnormal, and disassociation with such individuals (Picchioni & Murray, 2007). Negative expressed emotions characterised by hostility and criticism, along with faulty learning of aggressive or violent behaviours within the family also play a role in the negative behaviours displayed by people living with schizophrenia (Burke, 2012:228). Because of lack of knowledge about the disorder, people living with schizophrenia and their families are stigmatised, isolated, and even denied certain privileges (McInnis & Merajver, 2011:168).

The findings of the study revealed that participants’ adult children presented with a variety of aggressive, erratic and sometimes illogical behaviours which the caregivers did not know how to control. Based on the fact that the participants themselves do not have sufficient knowledge about schizophrenia, it is no surprise that they experienced

challenges with managing their adult children's behaviours. Once again further knowledge about the disorder is encouraged so that caregivers can know how to identify triggering behaviours and how to manage uncontrollable behaviours.

In order to understand behaviour, social construction of reality needs to be explored. Human behaviour is shaped by cultural and social constructs that highly influence decision making processes (Matthews, 2010:08). It is for this reason that explanatory theories of behaviour carry some sort of cultural or social construct within them. The Health Belief Model expands on this by indicating that health-related behaviour can never be understood without first exploring the personal belief systems held by an individual (Jones & Bartlet, 2004). Therefore, health behaviour will be impacted and influenced by the level of belief systems attached to specific conditions.

From this discussion, it can be pointed out that cultural factors play a major role in patient health seeking behaviour and preventative behaviours. The dual process of prevention and control of disease can therefore be linked to cultural connotations surrounding the disease itself. Emphasis on cultural awareness and sensitivity is still highlighted as an area of exploration in order to promote a better understanding of symptoms and explanations for diseases from a cultural perspective. Taylor et al. (2007:218) add that the Health Belief Model mediates for the confrontation of health-related behaviour from a personal belief system point of view, as personal belief systems are assumed to influence behavioural patterns and decision-making processes.

3.6.5 Theme 5: Programmes for mental health care users

Vocational programmes and exit plan caring facilities for mental health care users emerged as sub-themes during the study.

3.6.5.1 Sub-theme 5.1: Vocational programmes for mental health care users

Most participants expressed the need for vocational centres for their adult children. Participants mentioned this as follows:

- Participant A “...So, myself, I realised that we need centres, so that children can get resources for working with hands...I can fix a phone, I can do what, I can do what...”
- Participant F “...just little equipment so that children can be taught what they can know...”
- Participant G “eh, I want..., my child challenging, but I want u to knw, school is important. I started him with crèche, u knw a child that has problems”
- Participant I “even though it is difficult...but ya she participates in basketball and they went to Rustenburg to play...”

The above statements are supported by WHO (2012) which indicated that youth development centres should be the core services provided in communities. Youth development programmes are aimed at empowering youth with practical and theoretical skills, while at the same time curbing crime by removing them from the streets. The National Mental Health Policy Framework and Strategic Plan 2013-2020 (Department of Health, 2013) argues that mental health care services are neglected and as a result mental health care users are deprived of effective services to mobilise them to function within communities. It is argued that the move of mental health care users from institutions to communities was part of a bigger strategy to include them in programmes that were already facilitated within communities. This is in consensus to the White Paper for Social Welfare (RSA, 1997a) which seeks to promote a humane, social and just society, facilitate the meeting of basic human needs, and promote full participation in social, economic and political spheres to build human capacity and foster basic self-reliance. The exclusion of mental health care users from current available resources and services is a discriminatory behaviour that violates their rights. Mental health care users also need services that can empower them with skills to be able to function economically.

The researcher argues that the fact that the majority of the mental health care users have difficulties meeting main stream educational requirements means teaching them vocational skills, such as sewing, knitting, fixing appliances and so forth, becomes the only plausible alternative. The White Paper for Social Welfare (RSA, 1997a) strives for

economic freedom and stability and such skills are an engineering tool to meet such objectives. As indicated by the participants, knowledge on generating money will be beneficial in the process as a skill goes along with knowing how to manage finances. Entrepreneurial skills are among the most reported strategies on the news and other platforms, but there is no mention of such programmes for mental health care users.

The findings of the study emphasises the need for transparency in service delivery that is inclusive of all citizens, despite their health circumstances as indicated in the Constitution (RSA, 1996) and Bill of Rights. Programmes to be implemented in plight of perceived and experienced challenges for mental health care users can be effective only with a bottom-up consultation processes (RSA, 1997b). The Health Belief Model mediates for a consultation process as it allows for the exploration of personal accounts of mental health care users and their families from the point of view of their personal belief systems in explaining schizophrenia (Brieger, 2006:52). The Health Belief Model's focus on individual belief systems contributes positively to the promulgation and implementation effective programmes for mental health care users, as specific personal beliefs and experiences will be addressed.

The Health Belief Model contributes positively to the restructuring of health services, as it provides an understanding of health behaviour from a personal belief system point of view (Taylor et al., 2007). The model further suggests that adopting a cultural approach means that any population's cultural references and resources will be considered as key references in building a framework for strategies and project planning. This will in turn promote effective culturally sensitive programmes and projects in relation to schizophrenia (Taylor et al., 2007).

3.6.5.2 Sub-theme 5.2: Exit plan for mental health care users

The second sub-theme that emerged from theme five was caring facilities / exit plan for older mental health care users.

Participants indicated that they need exit plan strategies to be set in place for their adult children who are living with schizophrenia in order to have continuity of care for them. Participants expressed their views as follows:

- *Participant A “...once a child is released from the day care centre, then where does he go, what does he do, you understand...”*
- *Participant D “...they know money very well....you cannot know money and not know how it is generated...”*
- *Participant G “...they need something that will assure them that, when I am done here...”*
- *Participant E “...Mr grobler used to come and teach us how to handle these children, teach them skills, it is things we used to see...”*

There is a dearth of service centres for adult children above the age of 25 years old. Participants indicated the need for exit plans for their adult children, because when they reach the age of 21 they get released from the day care system. There has not been much research on this aspect either. Mental health care users end up staying at home without any form of education or skills development programmes due to their age. There has been recorded promulgation of programmes for mental health care users, but no form of implementation has been reported. Part of the proposed programmes was to make attempts to promote transparency of the community development programmes and services to mental health care users and their families through awareness and educational programmes. Mental health care users and their families are therefore involved in consultation processes and information giving sessions whereby they contribute to policy-making processes (RSA, 1997a).

Given the above discussions as exposed by the findings of the study, it is clear that mental health care users are still neglected in terms of service delivery in the country. There are many policies that have been proposed to address such inequities but the progress seems to be very slow, while the citizens are suffering in the meantime. The need for vocational centres is a great way of ensuring skilled and economically independent citizens. Such services should be at the core of the country’s mandate.

The South African legislation has partially achieved the objective of rights for mental health care users, as the treatment of mental health care users has improved. It is access to relevant services for such individuals and their families which are greatly neglected (Department of Health, 2013). The Health Belief Model still contributes in this regard as its nature of outlining individual needs and personal belief systems encourages legislative action steered towards the outcomes of the model. It has always been a known factor that addressing needs and challenges can only be successful when the personal accounts of those in need are explored. Therefore the Health Belief Model provides a platform for exploration of people's personal beliefs and accounts of schizophrenia; thereby promoting target-oriented and effective programmes.

3.7 SUMMARY

In summary, the study was guided by the research methodology as applicable to the study. The researcher analysed data through reading the transcripts until full saturation of the content of the interview. The findings of the study were then categorised and coded into themes and sub-themes as they emerged within the study.

Five themes emerged from the study, which was the understanding of schizophrenia, the causes of schizophrenia, the symptoms of schizophrenia, the challenges faced by parents as caregivers, and the mental health care user's programmes. Each theme was discussed in detail along with the sub-themes thereof. Direct quotations from the interview were used in the study to substantiate the emergent themes and sub-themes.

The findings of the study revealed the cultural beliefs of parents as caregivers of adult children living with schizophrenia. It was evident from the findings that parents as caregivers were observant of their adult children's symptoms and behaviours; experienced such challenges as lack of knowledge and understanding about schizophrenia and lack of services for mental health care users; and needed assurance about their adult children's future in terms of programmes. It is for these reasons that

the next chapter will embark on detailed conclusions and recommendations for the overall study.

CHAPTER 4 – CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter seeks to explain how the researcher achieved the goal and objectives of the study. The goal and objectives will be explored individually to show how they contributed to the conclusions that will be discussed at the end of the chapter. The researcher will elucidate on how the objectives were achieved by focussing on the findings of the study. This will lead to drawing of conclusions and making recommendations as guided by the findings of the study.

4.2 GOAL AND OBJECTIVES OF THE STUDY

The goal of the study was to explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia. The goal of the study was guided by the following research question:

“What are the cultural beliefs of parents as caregivers of adult children living with schizophrenia?”

The goal of the study was achieved through the attainment of the following objectives:

- **Objective 1:** To conceptualise mental illness in relation to cultural beliefs in rural African communities.

Based on the thorough literature study conducted in Chapter Two, the researcher was able to conceptualise mental illness in relation to cultural beliefs in rural African communities. The literature study yielded results that mental illness in African communities is believed to be a result of ancestral involvement and witchcraft.

Ancestors are believed to be communicating with their next of kin in the form of visions, dreams, reincarnation of spirits, and the “calling”. This results in people talking to unseen individuals, behaving in bizarre ways, or being in a trance. Such behaviours in Western culture are similar to symptoms of mental illness, specifically the symptoms of schizophrenia such as delusions, hallucinations and disorganised behaviour and speech.

The phenomenon of mental illness in relation to cultural beliefs is shaped by cultural connotations as experienced by a specific cultural group. The culture therefore provides specific explanations in terms of everyday experiences. McInnis and Merajver (2011:168) indicate that everyday experiences are explained according to cultural theories of specific tribes and those cultural beliefs differ from tribe to tribe.

- **Objective 2:** To explore the cultural beliefs of parents as caregivers of adult children living with schizophrenia.

The cultural beliefs of parents as caregivers of adult children living with schizophrenia have been explored through a comprehensive literature study and interviews conducted with the parents as participants. The phenomenon of cultural beliefs was explored in Chapter Three where participants indicated that cultural belief systems shape the understanding and explanation of mental illness. It was emphasised by the participants that witchcraft does indeed play a role in the development and manifestation of schizophrenia, whereby forces of jealousy and curses are used. The aspect of paternal aunts putting a curse on a child was emphasised, whereby it is believed that only such an aunt can be able to reverse the curse through ancestor rituals. This was supported in literature by Makau (2003:09), who asserts that indeed Africans believe that mental illness is caused by curses, witchcraft and elements of jealousy.

- **Objective 3:** To explore the needs and challenges of parents as caregivers of adult children living with schizophrenia.

The needs and challenges of caregivers have been recorded in few literature studies, ranging between social, financial and psycho-educational needs. The researcher explored this objective through interviews with participants. Chapter Three provides the participants' responses in terms of their identified needs and challenges in caring responsibilities.

It was evident from the findings of the study in Chapter Three that participants need more knowledge and understanding of schizophrenia as a disorder. Participants indicated the challenge of not fully understanding the diagnosis of their dependants. They expressed that they were only provided with clinical terms for their dependants' disorder and no further explanations were therefore provided to them. Participants indicated that not knowing how to control their dependants was a challenge and this was perceived to be caused by the lack of understanding of the complexity of the disorder. Furthermore, participants expressed difficulties in understanding the communication and behavioural patterns of their dependants.

The study further yielded results that caregivers are in need of vocational centres to empower their dependants with skills. Exit care options for dependants were also a major concern, as caregivers indicated the need for care placements to cater for their dependants who are above the adolescent age.

The researcher strongly believes that health care professionals are fully responsible for ensuring proper explanations of disorders to patients and family members, as they play a major role in ensuring the full recovery of patients. This statement is supported by the White Paper for Social Welfare (RSA, 1997a) which emphasises the need for families and communities to be consulted and educated on health programmes.

- **Objective 4:** To make recommendations for the improvement of social work services provided to parents who are caregivers of adult children living with schizophrenia.

The researcher embarked on an exploration of the cultural beliefs of parents as caregivers of adult children living with schizophrenia. The findings of the study in Chapter Three provided the researcher with factual and in-depth information that allowed the researcher an opportunity to draw up conclusions and recommendations. The conclusions and recommendations of the study are fully discussed in section 4.4 and 4.5 of this chapter.

In summary, the findings of the study indicate that there is indeed a correlation between mental illness and cultural beliefs. Culture shapes the mindset of communities, thus the explanations provided for health pandemics are notably influenced by cultural beliefs. The researcher points out that the cultural beliefs of caregivers are the cornerstone of the study, as their perceptions are shaped by what is considered to be reality to them. It is for this reason that cultural beliefs of parents as caregivers of adult children living with schizophrenia have been explored to explain the impact of these belief systems on the understanding of schizophrenia.

4.3 KEY FINDINGS OF THE STUDY

The key findings of the study were as follows:

- Schizophrenia is considered to be a mental illness that affects thought patterns.
- The findings have indicated that schizophrenia is common among people living in the rural areas, although in African communities it is interpreted differently due to cultural influences.
- Schizophrenia has been linked with witchcraft practices such as curses placed on a child by a paternal aunt. This is resolved through ancestral rituals by the

same aunt and the child has to be given an ancestral name that can make him/her easily identifiable by the ancestors.

- The study findings yielded the fact that parents as caregivers do not have sufficient knowledge about the phenomenon of schizophrenia, let alone how to control and manage the disorder.
- The study findings showed that a diagnosis of schizophrenia was ruled out by qualified medical doctors and psychologists as supported by literature.
- Clinical terms have been provided to participants without proper explanations of what the terms entail, thus leading to greater confusion.
- The study findings showed that caregivers face challenges when caring for their dependants, as they do not know how to control their dependants' behaviours.
- The study findings established that genetic, psychological, cultural, physiological and social factors play a major role in the development and manifestation of schizophrenia.
- The findings of the study showed that vocational programmes and care facilities are a major need for mental health care users.

In summary, the study yielded the findings that mental illness, specifically schizophrenia, is prevalent among Africans in rural areas. The interpretation of mental illness is defined and influenced by the cultural belief systems held by the individuals as supported by the Health Belief Model. In addition to cultural belief systems, social, psychological, physiological and environmental factors have been identified as playing a role in the development and manifestation of schizophrenia. Caregivers do not have sufficient knowledge about schizophrenia, thus influencing caring behaviours due to lack of knowledge on management and control of the disorder.

The overall results of the study blended very well with the Health Belief Model which emphasises that personal perceptions are influenced by a range of interpersonal factors affecting health behaviour (Lizewski, 2010). The study also confirms the findings of Jones and Bartlett (2004) who assert that the Health Belief Model is ideal for health promotion and health education. Therefore health care providers are influential in

motivating and promoting health seeking behaviour, adherence to treatment, and the promotion of preventative behaviours in the lives of parent as caregivers and their adult living with schizophrenia.

4.4 CONCLUSIONS OF THE STUDY

The following are the conclusions drawn up from the findings of the study:

- Despite South Africa's legislative progress for mental health, the researcher concluded that mental illness remains a public health pandemic. The services of mental health care remain limited to communities in need, especially those in the outskirts rural areas.
- It can be concluded that parents as caregivers for adult children living with a mental illness do not have sufficient knowledge about the disorder, thus they do not know how to manage or control their dependants.
- In view of the findings of the study, it can be concluded that health care professionals play a minimal role in ensuring proper understanding of the disorder to patients and caregivers as they do not provide sufficient information with regard to diagnoses.
- It can be concluded that genetic, psychological, physiological, socio-economic and environmental factors play a role in the development and manifestation of schizophrenia, as no single cause can be attributed to the disorder. It is therefore crucial that all aspects of human life be considered when making a diagnosis.
- The researcher concludes that there is evidently a link between mental illness and cultural beliefs. Cultural beliefs shape individuals' perceptions about everyday life experiences. Participants indicated the role of witchcraft and ancestral factors in development and manifestation of schizophrenia.
- The link between mental illness and cultural beliefs make it easily plausible for health care professionals to disregard the cultural aspect of diseases, as the symptoms of schizophrenia and those of cultural connotations such as speaking to unseen figures and disorganised speech are similar.

- The researcher concludes that there are limited programmes for mental health care users, especially skills development programmes, psycho-educational programmes, and aftercare services. As indicated in the study, services to mental health care users have been proposed through legislative processes, but not enough attempts have been made to implement the services. African communities are the most neglected in such instances, as they are marginalised due to their socio-economic status.
- The researcher further concludes that there are limited programmes for parents as caregivers of adult children focusing on schizophrenia in rural African communities. This was revealed mainly because mental health care users are excluded from family interventions by the Government. Furthermore, there is minimal mediation for the implementation of proposed programmes for mental health care users, specifically focusing on caregivers. As concluded in the study, parents as caregivers face the challenge of lack of resources for their adult children. This creates frustration and low morale in terms of positive health behaviour of these individuals. It is therefore imperative to note that as indicated in legislation, such as the White Paper for Social Welfare and the Constitution of the country, there should be equitable, non-decriminalised resources and services to all citizens.

In summary, it can be concluded that there is lack of knowledge about mental illness among caregivers. Health care professionals do not provide sufficient information to ensure a better understanding of schizophrenia. Caregivers experience such challenges as lack of knowledge on how to control and manage the symptoms and behaviour of their dependants due to minimal information regarding the disorder. There is evidence of lack of services rendered to mental health care users, their families and communities. In addition, it is of high importance for health care providers to understand the Health Belief Model in order for them to examine issues that encourage or discourage positive health seeking behaviours for parents as caregivers of adult children living with schizophrenia. This can only be achieved through cultural awareness and sensitivity. Jones and Bartlett (2004) indicate that health care providers should be aware that

people's beliefs about susceptibility to disease, and their perceptions of the benefits of trying to avoid it, influence their readiness to act, thereby concluding that individuals should be examined holistically.

4.5 RECOMMENDATIONS OF THE STUDY

The following recommendations were drawn up based on the key findings and conclusions of the study:

- It is strongly recommended that there should be educative support services for caregivers to ensure a better understanding of schizophrenia and what to expect when caring for their dependants.
- It is recommended that health care professionals need to be sensitised to their accountability in ensuring that mental health care users and their caregivers have a better understanding of schizophrenia. Health care professionals should make use of lay terms to explain the disorders to caregivers. Use of clinical terms should be thoroughly explained and used as little as possible to avoid the oversaturation of information of mental health care users and their caregivers.
- There should be psycho-educational training and support services offered to mental health care users, communities and families, especially parents as caregivers, in order to foster an understanding of mental illness, management and control of mental disorders, and caring options for mental disorders.
- There should be more training for health care professionals regarding different cultures in order to promote cultural sensitivity. Health care professionals are urged to be culturally sensitive to be able to consider the cultural aspects of each individual patient to make an accurate diagnosis.

- Health care professionals are not only expected to consider cultural factors, but also the environmental, socio-economic, psychological, and social factors when making a diagnosis. This will encourage accurate diagnoses, as no aspect of human life will be left out.
- It has been concluded that the Government should work in collaboration with the private sector in ensuring that mental health care users, their families, and communities are consulted and included in the development and implementation of policies and programmes aimed to address their specific needs.
- It is recommended that there should be strong collaboration between the Government and private sector to establish mental health services and programmes for mental health care users, their families, and communities.
- It is recommended that there should be skills development centres with programmes for mental health care users to empower more skilled labour and economically independent individuals. Care facilities catering for all ages should be established to assist caregivers in caring options for mental health care users. In addition, skills development programmes should be implemented for parents as caregivers for adult children living with schizophrenia to empower them with economic and life skills.
- Because social work strives for health promotion, social justice and equitable service delivery, it is imperative for social workers to play a direct role in the mediation for and empowerment of mental health care users, their families, and communicates. Social workers should be placed at the forefront of promoting self-investment of good health to mental health care users and their families through facilitation of group and community self-help programmes and psycho-educational programmes. Social workers should further ensure an awareness of schizophrenia by parents as caregivers of adult children, mental health care

users, health care professionals, and the communities at large through awareness campaigns and exhibitions.

- Finally, it is recommended that there should be further research on the phenomenon of schizophrenia and cultural beliefs. Research studies can focus on the influence of belief systems on mental illness, as this will assist health care professionals to be able to make accurate diagnoses and understand the disorders from the individuals' cultural backgrounds and perspectives. This will further assist in better management, control and guiding principles in terms of mental illness in relation to cultural belief systems.

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APPENDIX A



PHYSICAL ADDRESS: 1560 C
KLIPGAT

CONTACT: 083 733 6239
FAX NO: 0866129328

EMAIL ADDRESS: INF0@MFIHLAKALO.CO.ZA

Date: 25 November 2015

Attention: MS K.S MORAKE

RE: PERMISSION TO CONDUCT RESEARCH STUDY AT MFIHLAKALO SPECIAL SCHOOL

The management and governing body of Mfihlakalo Special School/Day Care Centre is pleased to inform you that permission has been granted to you and your research assistant to conduct a collective case study with 12 members of our organization. We note that the selected participants (Parents as caregivers of adult children living with schizophrenia) will be asked to attend two meetings that will take approximately 60 minutes per meeting. We take note that the goal of your study is to explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a day care centre/special school in the rural community of Klipgat, Pretoria in South Africa.

The organization has granted the permission for your request to use the school hall for the collective case study discussions so as to have a comfortable and conducive environment for the study. We acknowledge that we will not receive any monetary benefits for the use of our facilities and that no incentives or material benefits will be offered to our members (participants).

Thank you for choosing our organization. It is our hope that the study will contribute to a better understanding of mental health issues in relation to cultural beliefs, especially with development, awareness and inclusion.

Please do communicate with us and let us know when you are ready to commence with your study.

I trust that all will be well

Yours faithfully,

MR RONALD SESING
DEPUTY PRINCIPAL

APPENDIX B



Faculty of Humanities

Date:

LETTER OF INFORMED CONSENT FORM

SECTION A: Research Information

Title of the study: The cultural beliefs of parents as caregivers of adult children living with schizophrenia

Researcher:

Purpose of the study:

I have been asked to participate in a research study that is intended to explore *The cultural beliefs of parents as caregivers of adult children living with schizophrenia* The reason for participating is for the researcher to interview me in order to find out about

.....
.....

Procedures:

If I agree to participate, the following will occur:

I will be required to participate in an interview, in a venue and at a time that suits both me and the researcher. I will be contacted to arrange a place, time and date. The interview will be tape recorded with my permission and the data from the interview will be transcribed and for research purposes. A pseudonym or false name will be given to me and my identity will never be linked to the data or research report. The interview will take approximately one and half hours. I understand that there is no right or wrong answer and that the researcher purely wants my opinion. I understand that I will not benefit directly from this study. I will also not be compensated for my participation in this research study.

Confidentiality:

I understand that the data collected, which include the tape recordings and the transcribed interviews will be stored in the Department of Social Work and Criminology, University of Pretoria for 15 years. I also understand that my identity will remain anonymous. I also understand that data will be reported in the research report and scientific journals, but will not include any information that can identify me or any participants in this study. If at any point I experience any difficulties during or after the study I will contact the researcher.....

Please sign the consent form in the next page.

Kind regards

Researcher

Section B: Research Consent

I, _____ (Full name and surname of participant) hereby acknowledge that I have been informed about the research study. I am aware of what is required of me as a participant. I have read and understand how the process will be followed. I have asked questions I may have had and I am aware of the confidential nature of the study. As a participant I also understand that my identity will be kept anonymous. Finally, if at any point I choose to withdraw from the study I understand I will not suffer any negative consequences.

Participant:

Name and Surname: _____

Date: _____

Signature: _____

Researcher:

I had explained the study to the participant, and provided him/her with a copy of the participant information sheet.

Name and Surname: _____

Date: _____

Signature: _____

APPENDIX C

SEMI-STRUCTURED INTERVIEW SCHEDULE

Goal of this study

To explore and describe the cultural beliefs of parents as caregivers of adult children living with schizophrenia in a rural African community.

SECTION A: BIOGRAPHICAL DETAILS OF THE PARTICIPANTS

1. Age distribution

30-35 yrs		40-45 yrs		50-55 yrs		60-65 yrs		70-75 yrs	
-----------	--	-----------	--	-----------	--	-----------	--	-----------	--

2. Gender

Female		Male	
--------	--	------	--

3. Marital status

Single		Married		Divorced		Widowed		Living with partner	
--------	--	---------	--	----------	--	---------	--	---------------------	--

4. Language

Sepedi	Setswana	Sesotho	Xitsonga	Venda	English	Afrikaans	Other, specify
--------	----------	---------	----------	-------	---------	-----------	----------------

5. Sources of income (mark all those are applicable)

Social grant		Employed		Self employed		Partner		Other, specify

6. Number of dependents

1-2		3-4		5-6		7-8		9+	
-----	--	-----	--	-----	--	-----	--	----	--

7. Age distribution of dependents

19-25yrs		26-35yrs		36yrs+	
----------	--	----------	--	--------	--

8. Does your loved attend day care at Mfihlakalo Day Care Centre?

Yes		No	
-----	--	----	--

9. How many years are you caring for your loved one?

5 yrs		6yrs		7yrs		8 yrs+	
-------	--	------	--	------	--	--------	--

SECTION B: MENTAL HEALTH CARE

1. What is your understanding of schizophrenia?
2. Was your loved one diagnosed by a medical doctor?
3. What do you understand as the causes of schizophrenia?
4. What do you understand as the symptoms of schizophrenia?
5. How do you treat your loved one's condition?
6. Where do you get treatment for your loved one?
7. Do you feel that you get support from these people:
 - Family
 - Community members
 - Hospital staff- Nurses, social workers and doctors

Explain in what way you get support from these people.

8. What are the cultural explanations of schizophrenia?
9. How is schizophrenia culturally treated in you context?
10. What is the role of culture in treating your loved one's condition?
11. What are the challenges you experience regarding caring for your loved one?
12. Do you get the necessary support to address these challenges? Explain in what manner do you get support?

13. What are your needs regarding knowledge about schizophrenia?
14. What are your needs regarding caring for your loved one?
15. What are your recommendations regarding mental health services?

Thank you