

**PSYCHOLOGICAL STRATEGIES USED BY PEOPLE IN GA-DIKGALE COMMUNITY
TO MANAGE CHRONIC DISEASES**

by

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DEDICATION

This work is dedicated to all the people who aspire for greater things in life and wish to see themselves achieve beyond their predicted estimates. This work is also dedicated to my precious angel (my daughter) Thoriso Shadi Khwinana.

DECLARATION

I declare that **PSYCHOLOGICAL STRATEGIES USED BY PEOPLE IN GA-DIKGALE COMMUNITY TO MANAGE CHRONIC DISEASES** hereby submitted to the University of Limpopo, for the degree of Master of Arts in Clinical Psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Surname, Initials (Title)

Date

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ABSTRACT

A number of studies have indicated that psychological management of chronic diseases is important in order to assist a patient to cope with and manage their condition. The disease and the phenomenon around it can be explained as reasons why individuals move from one treatment facility to the other.

This study explored the psychological strategies used by people in Ga-Dikgale community to manage chronic diseases. A qualitative approach was followed and participants were selected through purposive sampling. Ten participants (five males and five females) who are receiving health care services for their chronic diseases were requested to participate in the study. Data were collected using semi-structured interviews and were analyzed using interpretive phenomenological analysis.

The results of the study are presented in terms of the following themes: participants' own explanations of chronic diseases; participants' subjective notions of the events or factors that could have led to their chronic diseases; what participants believe is the main causes of their disease(external or internal factors); pathways followed by the participants to manage their chronic disease; experiences of living with chronic disease; psychological coping strategies; the role of educational agencies; and implications for theory. The study revealed that chronic diseases are ambiguous in nature, with every individual explaining them in ways that relate to their personal experiences. For this reason there are different ways of managing or coping with them. Some people take on more active means of coping, while others are more passive.

TABLE OF CONTENTS

CONTENTS	PAGE
Cover page	
Dedication	i
Declaration	ii
Acknowledgements	iii
Abstract	iv
Table of contents	v

CHAPTER 1: INTRODUCTION

1.1 Introduction	1
1.2 Research problems	2
1.3 Aim of the study	2
1.4 Objectives of the study	3
1.5 Research question	3
1.6 Operational definition of concepts	3
1.7 Summary	4

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction	5
2.2 Chronic disease burden in South Africa	5
2.3 Cultural approaches to health, illness and healing	8

2.4 Psychological strategies to manage chronic diseases	10
2.5 Theories for managing chronic diseases	14
2.5.1 Attribution theory	14
2.6 Summary	16

CHAPTER 3: METHODOLOGY

3.1 Introduction	17
3.2 Research design	17
3.3 Sampling and setting	18
3.4 Data collection	19
3.5 Data analysis	20
3.6 Credibility, transferability etc	22
3.7 Ethical considerations	24
3.8 Summary	26

CHAPTER 4: RESULTS

4.1 Introduction	27
4.2 Demographic profile of participants	27
4.3 Phenomenological explication	29
4.4 Summary of findings	40

CHAPTER 5: DISCUSSION OF FINDINGS

5.1 Introduction	42
5.2 Emerging themes	42
5.3 Implications of theory	50

5.4 Summary	51
-------------	----

CHAPTER 6: SUMMARY AND CONCLUSION

6.1 Summary	52
-------------	----

6.2 Limitations of the study	53
------------------------------	----

6.3 Contributions and recommendations	53
---------------------------------------	----

REFERENCES	55
-------------------	-----------

APPENDICES

Appendix 1(a): Interview guide	63
--------------------------------	----

Appendix 1 (b): Interview guide in Sepedi	64
---	----

Appendix 2 (a): Participant consent letter and form	65
---	----

Appendix 2 (b): Participant consent letter and form in Sepedi	67
---	----

Appendix 3 (a): Consent form to be signed by the participant	69
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Appendix 3 (b): Consent form in Sepedi to be signed by the participant	70
--	----

Appendix 4: Interview	71
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CHAPTER 1

INTRODUCTION

1.1 Introduction

The chronic disease burden is rapidly increasing world-wide, and seems to be affecting all nationalities, races and genders. In 2010 the World Economic Forum (WEF) described chronic diseases as the biggest public health threat society has ever faced (WEF, 2010). According to Aikins, Unwin, Agyemang, Allotey, Campbell, and Arhinful, (2010), Africa's chronic disease burden is attributed to multifaceted factors including increased life expectancy, changing lifestyle practices, poverty, urbanisation and globalisation. Furthermore, a research study by Steyn(2005), has shown that the majority of the South African population has moved extensively along the epidemiology transition towards disease profiles that are more related to western lifestyles. However, the diseases of poverty, which are related to infectious and maternal disease, still contribute significantly to the overall burden of chronic diseases in South Africa. This epidemiological transition is motivated by people adopting unhealthy lifestyles, which relate to tobacco use, unhealthy nutrition, and lack of regular aerobic physical activity.

Chronic diseases are described as long-term, unpredictable in course, nature and outcome and have no defined cure(Martin, 2007). These illnesses cause strain on the individuals diagnosed with them and their families. Strains such as: financial problems, worry and stress, living in fear and other psychological problems. Chronic diseases may significantly impair everyday physical and mental functions and reduce one's ability to perform activities of daily living. According to Turner and Kelly (2000), patients with chronic conditions often have to adjust their aspirations, lifestyle, and employment amongst other things. Furthermore, many individuals grieve about their predicament before adjusting to it, but others have protracted distress and may develop psychiatric disorders, most commonly depression or anxiety.

1.2 Research problem

By their nature, chronic diseases lead to considerable distress in individuals leading to adjustment in a person's life. For this reason, many people with chronic diseases find it hard to manage the condition. Not only is dealing with the disease an uphill battle, so is the stress of related conditions that stem from the disease. Individuals with chronic health conditions are at greater risk of emotional and behavioural problems, including anxiety, depression, risk taking behaviours, body image and eating disorders, as well as social difficulties (Barlow & Ellard, 2006). On the other hand, chronic diseases today are still treated within a healthcare system dominated by the medical model, which primarily focuses on the illness and not on the person owning the illness. Treating chronic diseases from this perspective seems to be limited and frustrating for the patient. This possibly explains why some patients opt to seek other forms of help. The focus of this study is not on the illness per se, but rather on the experiences, mainly focusing on the psychological management strategies that individuals with chronic diseases use to manage their conditions and the beliefs and health attributions they have.

1.3 Aim of the study

This study was aimed at exploring cultural health attributions, including beliefs about the chronic conditions and psychological coping strategies that people with chronic diseases in Ga-Dikgale community utilize to manage their conditions.

1.4 Objectives of the study

The following objectives were identified for the study:

- To explore the meanings that people with chronic diseases attribute to their conditions; and,
- To investigate and describe the psychological strategies that people with chronic diseases use to manage their chronic diseases.

1.5 Research questions

The study sought to address the following research questions:

- What are the meanings that people with chronic diseases attribute to their conditions?
- What kind of psychological strategies are used by people with chronic diseases to manage their conditions?

1.6 Operational definition of concepts

- **Chronic illness:** Chronic illnesses are health conditions that either have symptoms on a constant basis or flare up episodically, such as: diabetes, heart disease, pulmonary problems, hypertension, stroke, cancer, obesity, mental disorders and some neurological disorders (Bedroussian, 2007). According to the World Health Organisation, (2005) chronic illnesses are illnesses of long duration and generally slow progression. In the context of the present study, chronic illness will mean those diseases that are non-curable but can be managed.
- **Health attribution:** It is defined as how individuals interpret events and how this relates to their belief systems with regard to health and healing (Vaughan, Jacquez, & Baker, 2009). These belief systems may include different disease models, wellness/illness paradigms, various culturally-specific diseases and disorders, and the use of traditional and indigenous healthcare practices and approaches.

- **Psychological strategies:** According to Hornby(2005) strategies are things that are done as part of a plan that is meant to achieve a particular purpose or to gain an advantage. In this study psychological strategies will refer to plans or actions an individual takes to gain advantage over their chronic illnesses.
- **Illness:** The state of being physically or mentally ill (Hornby, 2005).
- **Disease:** An illness affecting humans, animals or plants, often caused by infection (Hornby, 2005).
- **Coping:** To face and deal with responsibilities, problems, or difficulties, especially successfully or in a calm or adequate manner (Collins English Dictionary, 2014). Coping has also been defined as the things people do to avoid or minimize the stress that would otherwise result from problematic conditions of life (Pearlin&Aneshensel, 1986), and coping involves both having resources and using various coping strategies.
- **Coping strategies:** Refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events (Taylor, 1998).
- **Active Coping:** Active coping strategies are either behavioral or psychological responses designed to change the nature of the stressor itself or how one thinks about it (Taylor, 1998).
- **Passive Coping:** Passive coping strategies lead people into activities (such as alcohol use) or mental states (such as withdrawal) that keep them from directly addressing stressful events (Taylor, 1998).

1.7 Summary

The aim of the present chapter was to provide the background and to present the research problem that motivated the researcher to embark on the present study. The aim and the objectives, including the research questions that the study sought to answer are presented. The key concepts that will be used in the study also defined.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In this chapter, the researcher starts by discussing the nature and types of chronic diseases that dominate in South Africa. This will be followed by a discussion of cultural approaches of chronic diseases and some selected studies on psychological coping strategies for a number of chronic health related problems. In the last part of the literature review, the researcher focuses on the theory that is relevant to managing chronic diseases. This theory of attribution focuses mainly on disease theory systems or different things that chronic diseases can be attributed to and the beliefs that individuals hold towards their diseases.

2.2 Chronic disease burden in South Africa

According to the policy document on South Africa's primary health care (PHC), some chronic diseases are inherited while others can be caused by factors such as smoking, obesity, lack of exercise, alcohol consumption, poverty, genetic predisposition and malnutrition (Department of Health, 2003). For the Department of Health (2003), priority chronic diseases in South Africa to take note of are hypertension, diabetes type 2, asthma and strokes. These chronic diseases are reported to be prevalent in many parts of the country, and seem to be affecting more and more individuals.

2.2.1 Hypertension

According to Price and Kasner (2014) hypertension is a blood pressure greater than 140/90 mmHg. The prevalence of hypertension increases further with age, affecting 75% of people over the age of 70. Hypertension causes pathologic changes in the walls of small (diameter < 300 microns) arteries and arterioles usually at short branches of major arteries, which may result in either ischemic

stroke or intra-cerebral haemorrhage. Hypertension is aggravated by smoking, alcohol consumption, sodium intake, genetic factors, obesity and stress (Joubert & Bradshaw, 2004). Hypertensive emergency is defined as a blood pressure greater than 180/120 mmHg with end organ dysfunction, such as chest pain, shortness of breath, encephalopathy, or focal neurologic deficits (Price & Kasner, 2014).

2.2.2 Diabetes Mellitus

According to Medical News Today (2013) diabetes mellitus (sometimes called "sugar diabetes") is a condition that occurs when the body can't use glucose (a type of sugar) normally. Glucose is the main source of energy for the body's cells. The levels of glucose in the blood are controlled by a hormone called insulin, which is made by the pancreas. Insulin helps glucose enter the cells. In diabetes, the pancreas does not make enough insulin (type 1 diabetes) or the body can't respond normally to the insulin that is made (type 2 diabetes). This causes glucose levels in the blood to rise, leading to symptoms such as increased urination, extreme thirst, and unexplained weight loss.

2.2.3 Cancer

Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells can spread to other parts of the body through the blood and lymph systems. There are more than 100 different types of cancer. Most cancers are named for the organ or type of cell in which they start (National Cancer Institution, 2013)

2.2.4 Arthritis

Arthritis is a form of joint disorder that involves inflammation of one or more joints. There are over 100 different forms of arthritis. The most common form, osteoarthritis (degenerative joint disease), is a result of trauma to the joint, infection of the joint, or age (Medical News Today, 2013).

2.2.5 Asthma

Asthma is a disease affecting the airways that carry air to and from your lungs. The inside walls of an asthmatic's airways are swollen or inflamed. This swelling or inflammation makes the airways extremely sensitive to irritations and increases your susceptibility to an allergic reaction. As inflammation causes the airways to become narrower, less air can pass through them, both to and from the lungs. Symptoms of the narrowing include wheezing (a hissing sound while breathing), chest tightness, breathing problems, and coughing (Medical News Today, 2013).

2.2.6 Strokes

Medical News Today (2013) describes a stroke as a condition in which the brain cells suddenly die because of lack of oxygen. A stroke can be caused by an obstruction in the blood flow or rupture of an artery that feeds the brain. There are two main types of strokes, namely Ischemic and hemorrhagic strokes. Ischemic strokes occur when a blood clot, or thrombus, forms that blocks blood flow to part of the brain. Hemorrhagic strokes occur when a blood vessel on the brain's surface ruptures and fills the space between the brain and skull with blood (subarachnoid haemorrhage) or when a defective artery in the brain bursts and fills the surrounding tissue with blood (cerebral hemorrhage). Following a stroke the patient may suddenly lose the ability to speak, there may be memory problems or one side of the body may become paralysed.

According to Househam (2010), the World Health Organization (WHO) estimates place the burden from chronic diseases in South Africa as two to three times higher than that in developed countries.

2.3 Cultural approaches to health, illness and healing

The Collins English Dictionary, (2014) describes culture as inherited beliefs, values, and knowledge which constitute the shared bases of social action. This means that members of a cultural group share characteristics that distinguish them from other groups. So, it is evident that culture is a way of living, thinking, and behaving. According to Mc Laughlin and Braun (1998), culture is learned within the family and guides the way we solve problems and live our daily lives. Culture includes many elements, including language, customs, beliefs, traditions, and ways of communicating.

Vaughn, Jacquez, & Barker, (2009) suggest that culture influences health and healing practices. They further pointed out that all cultures have systems of health beliefs to explain what causes illness, how it can be cured or treated, and who should be involved in the process. Cultural influences affect not only perspectives on health, illness and disease (e.g. patterns of diseases) but also a variety of health related behaviours, such as, beliefs that underlie the utilization of services , seeking of medical care, responses to pain, responses to symptoms, and the use of traditional healers (Freeman and Motsei, 1992). Pillay, (1993) supports this view by stating that beliefs and attitudes influence health behaviour. Furthermore, he adds that cultural and social beliefs also influence the way health care facilities are used. Furnham, (1999) also examined health beliefs across the three cultures of Britain, Uganda and South Africa and found that the African participants were more likely to attribute illness to “evil others” but all of the groups rated interpersonal stress as a potential source of illness.

Maraich (2003) observes that every human society has its own cultural system(s) for responding to diseases and restoring health to individuals who are ill. The various cultural realities people have constructed, whether these be in terms of beliefs, values, languages, institutions, customs, labels and laws, all have significant influence in human functioning, and therefore, in how health is defined. Significant differences exist regarding the conceptualization of chronic

disease between the indigenous African and Western people. These differences can be attributed to differences in social, cultural, economic, and historical conditions. According to Vaughn, Jacquez, & Barker (2009) westerners tend to attribute the cause of illness to the individual or the natural world, whereas individuals from non western nations are more likely to explain illness as a result of social and supernatural causes. Western approaches explain illness and disease as having biological etiology, these include genetic damage, biochemical imbalances, and infections (Torrey, 1986). The conceptualization of illness, according to South African black individuals on the other hand, is more complex, including, biological, social, religious, and magical factors (Dempster, 1982). Although western medicine plays a dominant role in the mass control of disease, traditional or folk medicine continues to play an important role in the health care of black communities (Pillay, 1993).

According to Cheetham and Griffiths, (1982) African people regard the human organism as a whole which is integrated with the total ecology of the environment and with the interrelated spiritual, magical and mystical forces surrounding the individual. They go further to explain this difference by saying ideas about health and illness are grounded in culturally based understandings. The subjective meaning of illness is influenced by intrapersonal, illness-related and environmental factors. These interpretations of illnesses may have an influence on preferences in decision-making and choice of coping strategies. Cultural issues play a major role in patient compliance to medication or proper health maintenance. This is because cultural differences affect patients' attitudes about medical care and their ability to understand, manage and cope with the course of an illness, the meaning of a diagnosis, and the consequences of medical treatment (Mc Laughlin & Braun, 1998).

2.4 Psychological strategies to manage chronic diseases

According to Sarafino (1994), studies have shown that psychological and biological systems are interrelated, that is, as one system changes, the other is often affected. This means that individuals with chronic health conditions are at great risk of emotional problems, behavioural problems, as well as social difficulties (Ross, Malthus, Berrett, & Harvey, 2009). Depression, feelings of frustration, confusion, anger about the illness, and a sense of being out of control are some of the most frequent emotional effects of being diagnosed with a chronic condition (Smith, Harre, & Langenhoven, 1995). Individuals can also be affected by stigmatization that stems from the disorder, fear of being labelled or diagnosed and the fear of transmission or progression of the disorder. These psychological issues can impact on an individual's ability to cope with their physical condition. Family members of an individual with a chronic health condition are also at risk of psychological distress (Ross et al., 2009). Philips and Rachman (1996) argue that once a problem becomes chronic, psychological factors increasingly become important in its understanding and management.

Despite the effects of chronic diseases, patients have to find ways to maintain physical, emotional and spiritual health despite the long-lasting course of the illness. According to Bussing, Ostermann, Neugebauer, and Heusser (2012) there are different ways to cope with a chronic disease with the most common being passive and active coping strategies. Coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events. Active coping encompasses problem solving; collecting information and refocusing on the problem, or regulating of emotion by focusing attention on the emotional response aroused by the stressor. These methods are likely to lead to less pain, less depression, less functional impairment, and higher general self-efficacy, while passive coping (that is, avoidance and escape) can be in the form of drug and alcohol use or withdrawal.

Passive coping is correlated with reports of greater depression, greater pain and flare-up activity, greater functional impairment, and lower general self-efficacy. Other important factors needed for coping with chronic diseases are communication and emotional expressiveness, role relationships, available caregivers, and financial resources. Generally speaking, active coping strategies, whether behavioral or emotional, are thought to be better ways to deal with stressful events, and passive coping strategies appear to be a psychological risk factor or marker for adverse responses to stressful life events.

2.4.1 Internal resources used to cope with chronic diseases

The nature of a chronic disease demands sufferers to adjust continuously to the degenerative nature of the illness and its consequences. As a result of her work with cancer patients, cardiac patients and rape victims, Taylor (1983 as cited in Viviers, 2005) proposed a theory of cognitive adaptation to threatening events. Taylor defined an adjustment process that centers around three themes; namely a search for meaning in the experience, an attempt to regain mastery over the event in particular and over one's life, and an effort to restore self-esteem through self-enriching evaluations.

A. The search for meaning

According to Viviers, (2005), the search for meaning involves the need to understand why a crisis has occurred and what its impact has been. People confronted with a threatening event like a personal illness will make attributions in an effort to understand, predict and control their environment. People will try to establish the cause of the event; by understanding the cause they may find the significance of the event in their lives and realise what it symbolises in their life. The search for meaning also involves the exploration of the implications of the illness and its consequences for one's life.

In a study focusing on preventing mental health problems among children with chronic diseases, Patterson and Geber (1991) points out that meaning is at the core of determining whether a disability leads to a handicap, which is a discrepancy between role expectations and actual role performance. This definition allows people with chronic diseases and their families to experience the illness with meaning.

B. Gaining a sense of mastery

A sudden threatening event like a chronic disease can easily undermine one's sense of control over one's body as well as one's life. The adjustment process involves gaining a feeling of control over the illness. A sense of mastery may be achieved by beliefs of personal control over the illness or direct behavioural efforts to control the illness. According to Viviers (2005) a person may control the illness by gaining knowledge of it, or changing his or her diet or by following health professionals' advice thoroughly.

If an individual attributes that their illness is personally caused, they are more likely to lean on internal resources that include: maintaining hope, normalization of symptoms, defining the illness in a positive manner, and leading a conscious way of living. According to Turner and Kelly (2000), for patients and their families, hope is an integral part of coping with many chronic diseases. This was evident in long-term survivors of HIV infections (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996) and long-term survivors of breast cancer (Rabkin, Remien, Katoff, & Williams, 1993). With normalization the individual, attempts to normalize the situation by minimizing the illness and conveying the impression of normalcy to others. In this way the individual with the disorder feels as though they have mastered their condition and have things in control. In the same way they may as a means of mastering the illness define the illness in a positive manner. It is also an effort to maintain a certain balance in family life. Conscious Way of Living addresses cognitive and behavioural strategies in terms of internal powers and

virtues (i.e., healthy diet; physical fitness; living consciously; keep away harmful influences; change life to get well). Conscious way of living can also include a person taking on a positive attitude.

C. The process of self-enhancement

The third theme in the process of adjustment involves the efforts to enhance the self and restore self-esteem. Being confronted with a threatening event such as illness may lead to a drop in self esteem and self-regard. In illness, after such a drop in self-regard is experienced, people tend to use cognitive efforts to pull themselves out of their low self-regard. In her study, Taylor (1983) reports some of the esteem-enhancing cognitions participants used to restore self-esteem and self-regard. Social comparison contributed to the self-enhancing efforts of patients in Taylor's study. Comparing one's self to someone that you believe is worse off is a self-enhancing cognition to bolster self-esteem. Dewar and Lee (2000) reported a similar strategy in patients with severe spinal injuries of boosting self-esteem by comparing themselves to those who were regarded worse off than you. Successful self-enhancement in the process of adjustment depends on the ability of the individual to sustain and modify cognitions or illusions that buffer against the present threat of illness as well as against possible future setbacks.

2.4.2 External resources used to assist individual in coping with chronic diseases

For those who believe their illness is caused by something out of themselves, they will lean on something outside to help with the disease. Some people may trust in a higher power (God), while they pray to become healthy again and live in accordance with religious convictions. Other people may alternatively trust in the therapeutic potentials of modern medicine, take prescribed medication, and show full confidence in doctors and therapists. Others can even decide to thoroughly research about the disease; get thorough information how to

become healthy again; find people who can help and search for alternative ways of healing (Bussing et al., 2012).

2.5 Theories for managing chronic diseases

2.5.1 Attribution theory

Like any behaviour, the heart of health behaviour is attributions. Bradley 1985 (cited in Ogden, 2004) examined patients' attributions of responsibility for their diabetes and found that perceived control over their illness (is the diabetes controllable by me or a powerful other?) influenced their choice of treatment. Those who attributed the illness to themselves, sought for more hands on treatment, whereas others did not.

As we know different cultures attribute different chronic diseases to different things. Some cultures are more likely to attribute their diseases externally to God's will or destiny, and this will lead them to believe in the healing power of prayer. While other cultures are more likely to attribute their diseases to more individual responsibility and account more empirical reasons for the health problems. For this reason these individuals believe that illness can be managed without reference to family, community or deities (Vaughn, Jacquez, & Barker 2009).

According to Vaughn, Jacquez, and Barker(2009), health attributions influence health beliefs and subsequent health behaviours. As mentioned already, people of diverse cultural backgrounds often make different attributions of illness, health, disease, symptoms and treatment. This relationship in turn becomes reciprocal and health beliefs form a cognitive schema that influences the way that people make attributions. According to Madge, (1998 cited in Vaughn et al., 2009) in comparison to Western populations, African patients may be more likely to attribute illness to a spiritual or social cause rather than a physiological or

scientific cause. As such, medical practitioners in many African countries emphasize the whole person-body, mind and soul approach.

2.5.2 Disease theory systems (Personalistic, emotionalistic and naturalistic attributional styles)

From the above information, it can be argued that all cultures have disease theory systems that include attributional concepts to explain illness causality. Directly this will mean that all cultures have attributional concepts to explain management of chronic diseases. Three commonly held paradigms of disease across cultures are naturalistic, personalistic and emotionalistic. Naturalistic disease theories explain disease in objective, scientific terms and have the core concept that illness occurs when the body is out of balance. Personalistic disease theory attributes illness to intervention by an agent such as another human, witch, sorcerer, non-human, or supernatural force. Emotionalistic disease theories explain illness as caused by strong emotional states (e.g., intense anger, jealousy, shame, grief or fright). The personalistic and emotionalistic disease theories are easily applied to patients of non-Western cultural backgrounds who are familiar with and have faith in the medical beliefs and practices from their own cultures (Foster, 1974).

2.5.3 Illness beliefs

Leventhal and colleagues in Ogden (2004), defined *illness beliefs* as a patient's own implicit, beliefs about his or her illness. They proposed that these beliefs provide a framework, or schema, for coping with and understanding an illness, and for telling us what to look out for if we believe that we are becoming ill. Once ill, people also hold beliefs about their illness and will cope in different ways. For example, if someone believes 'my heart attack was caused by my genetic makeup', they may cope by thinking 'there is nothing I can do about my health; I am the victim of my genes'. Beliefs like this are likely to influence the progression of the illness either by affecting behaviour or by having an impact on the immune system.

Chipfakacha (cited in Vaughn et al.,2009)notes that most black Africans attribute illness to superstitious causes and therefore believe that illness is due to : (in order of relevance) 1) magic and evil spirits; 2) conditions for which causes have been empirically determined; and 3) psychological phenomena. For many Africans, the cause of illness relates to conflict and tension between good/evil and harmony/ disharmony (Vaughn et al. 2009).

2.6 Summary

In this chapter, some chronic health conditions that are common in South Africa were discussed. Cultural approaches to health, illness and healing and psychological strategies to manage diseases (active, passive, internal and external) were explored. Lastly the chapter looked at specific theories that can be used to manage chronic diseases.

CHAPTER 3

METHODOLOGY

3.1 Introduction

The main focus of this section is on the methodology employed in this study. According to Mostert (2012), it is important to describe the research design and methodology as the method of inquiry will influence the scientific value of the results. The sampling, data collection method and procedures, and the data analysis methods are presented. The researcher concludes this section with a brief overview of ethical issues that were met when conducting the study.

3.2 Research design

In this exploratory study, a qualitative research approach, that of a phenomenological nature was employed. Qualitative research has been recognised as a legitimate way to obtain knowledge that might be hard to access by other methods and to provide extensive data on how people interpret, and behave in relation to their symptoms (Smith, Pope, & Botha, 2005). Qualitative research is subjective as it seeks to understand human behaviour and reasons that govern such behaviours. It is therefore conducted in a natural setting and it involves a process of building a complex and holistic picture of the phenomenon of interest. It further does not usually describe data in the form of numbers, but is an inductive approach, and its goal is to gain a deeper understanding of a person's or a group's experience (Creswell, 2003).

De Vos, Strydom, Fouche, and Delport, (2005) describe the phenomenological approach as a descriptive study on how individuals experience a phenomenon. With the purpose being to illuminate the specific, to identify phenomena through how they are perceived by the actors in a situation (Lester, 1999). This normally translates into gathering 'deep' information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation,

and representing it from the perspective of the research participant(s). According to Lester (1999), phenomenological approaches are based on a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation. As such they helpful in understanding subjective experiences, gaining insights into individual's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom. Furthermore phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions.

3.3 Sampling and setting

The participants in this study were selected from Ga-Dikgale community. Only participants who were previously diagnosed with chronic diseases were selected, through purposive sampling, which is a type of a non- probability sampling technique. In purposive sampling, cases are selected because they illustrate some features or process that is of interest for a particular study (Silverman, 2000) and researchers will be having a clear criterion in mind and have rationale for their decisions (Creswell, 1998). Because the participants are chosen specifically meeting certain requirements, purposive sampling was found to be appropriate for the present study as the aim was to gain an in-depth understanding of people's experiences.

The population in the study comprised of persons within the existing database of the UL-VLIR partnership research programme that have been diagnosed with different chronic diseases. The programme is a partnership between Flemish Universities and the University of Limpopo, with the University of Antwerp as principal partner. The programme is a multidisciplinary comprehensive package that supports and integrates five project clusters whose overarching theme is: "Human wellness in the context of global change – finding solutions for rural Africa". The bigger research project by Dr Makhubele and Prof Sodi entitled "The impact of lifestyle behaviours on chronic diseases: The case of Ga-Dikgale

Communities”), is located in Cluster 2. The aim of this research project (also known as Project 2) is to explore and describe various lifestyle behaviours and chronic diseases in Ga-Dikgale community (Limpopo Province).

3.4 Data collection

An interview guide was developed as a tool to gather data. According to Rubin and Babbie (2001), an interview guide ensures that the interviewer covers the same material and keeps focused on the same predetermined topic and issues, while at the same time remaining conversational and free to probe into unexpected circumstances and responses. The interview guide was self-developed based on the appropriate literature and research (see Appendices 1(a), (b)). The interview guide focused on exploring the conceptualizations of these participants into their chronic diseases. Their subjective understandings, experiences, and beliefs of chronic diseases, events or factors that could have led to their diseases as well as treatment and management seeking processes.

Semi-structured one-to-one interviews were conducted at locations that were suitable for the participants. One of the participants a 11 year old male who was diagnosed with epilepsy from birth was unable to communicate, so her mother was interviewed on her behalf. Some participants were interviewed at their homes, while others were interviewed at Ga-Dikgale clinic (doctors consulting room). The two locations were chosen due to accessibility, availability and convenience to the different participants. Some participants collected medication at the Ga-Dikgale Clinic, and it was therefore convenient for them to be interviewed at the clinic. The interview process did not disturb their usual clinic routine because they were interviewed before seeing the doctor.

According to Smith et al.,(cited in De Vos et al., 2005), semi-structured one-to-one interviews give both the researcher and participant more flexibility and is suitable where the researcher is particularly interested in complexity or process, or where an issue is controversial or personal. The fundamental assumption in

this method is to converse with the aim of exploring the general topics in order to uncover the participants meaning and perspective. By using this method, the researcher respects the participants' own framing and structuring of responses. The phenomenon studied should unfold in accordance with the participant's way of viewing the phenomenon and not the researcher's view.

In the interviews with the participants their age, gender, religion, current medical stance (duration of diagnosis and status of illness), and duration of treatment was acquired. This was an important aspect of the research as it revealed the social meaning and interpretation of illness. In addition, through the responses one could get a sense of how the participants in this study felt. Data were captured through tape recorders and written notes, in accordance with Collins (1998), recommendations that the events recounted and experiences described are made more substantial and real through recording and writing of notes.

The length of the interview differed from one participant to the other. This was mainly determined by the replies they gave. Though the participants shared the fact that they were all diagnosed with a chronic disease, some participants gave more information in comparison to others. It was evident in the study that participants were comfortable speaking in their own languages and seemed to relate their experiences with ease. Most of the participants relayed that they were comfortable and felt free to talk due to the confidential nature of the different venues. The researcher also felt free to probe and ask further questions from the interview guide. The participants were cooperative, and responded satisfactorily.

3.5 Data analysis

According to Marshall and Rossman (1999), data collection and analysis typically go hand in hand in order to build a coherent interpretation of the data. This means that ideas for making sense of the data emerge while still in the field of collecting data. The researcher looked at frequently recurring patterns of

responses and themes. The collected data were organized (Creswell, 1998) and interviews or notes transcribed.

The interviews were conducted in the participants' home language, namely, Sepedi so as to ensure that they fully understood the content of the interviewing process and thus relate their experiences adequately. Based on the aforementioned state of affairs, the data were translated from Sepedi into English by a Sepedi-speaking language expert. Back-translation was also done to ensure that there was consistency in meaning of both the English and Sepedi versions of the data. The tape recording was then given to the researcher's supervisor to listen to and to repeat the above process for the sake of validation.

Interpretative phenomenological analysis was used to analyse the data. This method of data analysis focuses on the cognitive processing of the participants. It is concerned with exploring meaning-making rather than information processing (Marks, Murray, Evans, Willig, Woodall, & Sykes, 2005).

The data were analysed in the following steps:

Step1: Familiarisation and immersion: The researcher read through the interview transcripts and annotates it. This entailed making notes, drawing diagrams, brainstorming and immersing in the material.

Step 2: Inducing themes: The researcher then re-reads the text and develops a higher order thematic analysis by inferring general rules or classes from specific instances. Having identified the key themes or categories, the researcher then proceeded to look for connection between them by identifying clusters.

Step 3: Coding: Coding involves breaking up the data in analytically relevant way. This entailed marking different sections of the data as being instances of, or relevant to, one or more of the themes.

Step 4: Elaboration, interpretation and checking: In this step the researcher keeps on coding, elaborating and coding until no further significant new insight appear to emerge.

Step 5: Presentation of results: This was the final stage which is regarded as the primary mode for reporting the results of the research. In the present study, this step included writing account of the phenomenon studied. During this step, the researcher presented data (a packaging of what was found) in text form.

3.6. Credibility, transferability, confirmability and dependability

Qualitative research has often been criticized for being subjective and therefore rather hard to replicate. Thus, findings are sometimes considered to be lacking reliability. Reason and Rowan (1981) assert that validity in qualitative research lies in the emphasis on the personal encounter with the experience and encounter with persons. Another critique against qualitative research is that the subjectivity makes it run the risk of projection and collusion that may have a negative impact on both reliability and validity of the study. Craftsmanship is an important tool in qualitative research as it ensures validity and safeguards against imposition by the researcher (Denzil & Lincoln, 2000). Craftsmanship is described as the researcher's qualification, his/her competent observation and the ability to accurately record and transcribe the data. In this study, the interviews were recorded. The tapes were played and recorded word for word. The transcripts were read over a couple of times to get the general idea of the data. Small summary notes were then written on the margins of the prescribed interviews. Mischler (1990) refers to this process as the trustworthiness of the procedure whereby the raw data are transcribed into manageable data and results. To ensure reliability in qualitative research, examination of trustworthiness is crucial. Seale (1999), while establishing good quality studies through reliability and validity in qualitative research, states that the "trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability.

3.6.1 Credibility

In qualitative research, credibility is maintained by an inquiry that ensures that the subject is accurately identified and described (de Vos, 2002). The researcher adequately placed boundaries around the study, by adequately stating the parameters such as the variables, the population and theoretical framework Marshall and Rossman, (1999 as cited in Shai, 2012).

3.6.2 Transferability

Transferability refers to the applicability of one set of findings to another context (de Vos, 2002). In this study, the researcher used multiple methods of data collection namely, interviews and recordings. This has led to more valid, reliable and diverse construction of realities and it can be viewed as a way of strengthening the study's usefulness for other settings. The researcher further accounted for information gathered with a very detailed manuscript in order to strengthen the study's transferability.

3.6.3 Confirmability

Marshall and Rossman, (1999 as cited in Shai, 2012) emphasize the need to ask whether or not the findings of the study could be confirmed by another. The researcher involved several peer researchers to assist with interpretation of the data at different times or location, so as to improve the analysis and understanding of construction of others.

3.6.4 Dependability or trustworthiness

Shenton (2004) describes that it is important to know if the study can be replicated in another form or setting. In order to address the dependability issue the processes within the study were reported in detail, thereby enabling future researchers to repeat the work though not necessarily to gain the same results. Thus, the research design maybe viewed as a “prototype model”. Such in-depth coverage also allows the reader to assess the extent to which proper research practices have been followed.

3.7. ETHICAL CONSIDERATIONS

3.7.1 Informed consent

Participants were informed about the aims and objectives of the research. They were further informed about their choice in participating and their right to withdraw at any given time. This helped to ensure that they fully understood the investigation and were consequently able to make voluntary decisions about their participation (Hakim, 2000, as cited in De Vos et al., 2005). The participants were further informed that the interviews were recorded. The researcher informed the participants that they could terminate their participation in this study at any point, should they not want to continue, and clearly indicated that this decision would not in any way affect them negatively (see Appendices 2 (a)(b) and Appendices 3 (a), (b)).

3.7.2 Confidentiality/anonymity and privacy

As it is the responsibility of the researcher to ensure that the privacy and identity of the research participants is safeguarded, the information (recordings and transcripts) obtained was handled in a confidential manner. The names of the participants were not included on the consent forms, instead participants were labelled in sequence from participant 001 to 010, in order to keep their

identification private. As the participants were being interviewed, they were interviewed in a private setting where only themselves and the researcher were able to hear their responses.

3.7.3 Respect for persons

The researcher ensured that the dignity of all the research participants was respected by ensuring that they were not used simply as a means to achieve research objectives, but to benefit from the knowledge derived from the study.

3.7.4 Debriefing or referral for the participants

In the initial plan, the researcher gave an allowance for the possibility of debriefing sessions to be held, and appropriate referrals be made should a need arise. These sessions were meant to provide participants with the opportunity to work through their diseases and the aftermath of these experiences. During the interviewing process, using her skills and expertise as a training clinician, the researcher was able to assess the situation. The emotional problems that seemed to have been generated by the research experience were dealt with or corrected after the interview.

3.7.5 Permission to conduct the study

Prior to commencement of the research, ethical clearance for the bigger study (of which the present study is a small part) was obtained from the University's Research and Ethics Committee. Permission was also acquired for the present investigation.

3.8 Summary

In this chapter a detailed description of the methodology used in the study was given. Further more the sampling, data collection method and procedure, and the data analysis methods were presented. Lastly the ethical issues were outlined.

CHAPTER 4

RESULTS

4.1 Introduction

In this chapter, the researcher will first present the demographic profile of the participants. This will be followed by phenomenological explication of the protocols obtained from the participants so as to extract the psychological themes that emerge. The themes highlighted in this chapter seem to be central to the experience of living with a chronic disease. The participants in this study were diagnosed with different chronic diseases and were interviewed at different stages in the progression of their illness (see Table 1). This impacted on their different experiences and made each story unique.

This chapter will explore the main themes related to the participants' experiences of living with a chronic disease that emerged from the texts.

4.2 Demographic profile of participants

The sample of this study comprised of ten (10) participants who are receiving health care services, and have been diagnosed as suffering from a chronic disease. This includes one participant who could not communicate effectively, so her mother was interviewed on her behalf. There were five males (50%) and five females (50%) included in the study. The participants' ages ranged from 11- 74 years. Their mean age was 51. The selected participants were included in the sample because they were all living with chronic diseases and had experiences around that. The distribution by ethnicity and location showed that all (100%) the participants were Sepedi-speaking from Ga-Dikgale community. They were all living with chronic diseases, and the period varied from one individual to the next. The longest period was 14 years, while the shortest was 2 years (see Appendix 4).

Participant	Age	Gender	Home Language	Residential Area	Religion	Chronic disease(s)/ Diagnosis
1	74	Female	Sepedi	Ga- Dikgale	Christian (Z.C.C)	Sugar diabetes and High blood pressure
2	64	Female	Sepedi	Ga- Dikgale	Christian (Nazarene)	Sugar diabetes and High blood pressure
3	58	Female	Sepedi	Ga- Dikgale	Christian (Z.C.C)	High blood pressure
4	37	Female	Sepedi	Ga- Dikgale	Not Available	HIV/ AIDS
5	11 (mother 45)	Female	Sepedi	Ga- Dikgale	Christian (Born again)	Epilepsy
6	64	Male	Sepedi	Ga- Dikgale	Traditional	Sugar diabetes and High blood pressure
7	71	Male	Sepedi	Ga- Dikgale	Not available	Sugar diabetes and High blood pressure
8	32	Male	Sepedi	Ga- Dikgale	Not available	Schizophrenia
9	68	Male	Sepedi	Ga- Dikgale	Christian Z.C.C	High blood pressure
10	31	Male	Sepedi	Ga- Dikgale	Christian (Lutheran) Yet consulting at Z.C.C church	High blood pressure and Schizophrenia

- Participant 005 was 11years of age and due to the disease her communication was affected, so the participants mother was interviewed.
- Not Available in the above table refers to those individuals who do not have a religious preference.

4.3 Phenomenological explication

4.3.1 Participants' own explanations of chronic diseases

Less than half of the participants in this study were able to give an explanation of what they understood were chronic diseases and in their accounts, made use of various descriptive words and phrases related to their own experiences, such as the symptoms they experienced during the course of the distress. The following quotes illustrate some of the examples of the explanations given:

*“Chronic diseases are illnesses caused by old age or food that we eat. These days we do not eat like we did back in time, now we eat foods that have spices and fats. Even in food such as cabbage and rice we put in oils and just eat and this is not good for us, especially we older people. I personally do not like things that have fat anymore, things such as fat cakes or pumpkin, especially when it has sugar”***(Participant 001)**

“If you sleep with someone who has lost their child (miscarried or abortion), you will get a condition called Makgoma” **(Participant 004)**

*“These are conditions in which one will continue drinking medication forever. If you stop the medication you will die.”***(Participant 007)**

The rest of the participants were unable to explain what chronic diseases are.

4.3.2 Participants' subjective notions of the events or factors that could have led to their chronic diseases.

The findings from the study suggest that people suffering from chronic diseases have their own perceptions and beliefs about the events or factors that could have led to their illnesses. These perceptions appear not only to be specific to an individual but also to be ambiguous, and they include amongst others, a wrong diet, genetics and social stressors. Everyday stressors such as death or illness of a loved one, unemployment, family discord, pre-existing general medical conditions and occupational problems are also perceived to be contributing to the

chronic condition. The following quotations from the interviews corroborate their experiences:

*“I believe that these conditions stem from stress or thinking too much. I remember that my sibling passed away while I was already diagnosed and when that happened I was admitted in Mankweng hospital due to the fact that my sugar was around 24.8, because I was hurt and therefore, I was under stress.”***(Participant 002)**

*“Problems that bother a person, causing them to constantly talk to themselves and worry.”***(Participant 003)**

*“I personally was involved in some accidents when I was younger and I spent some time sitting at home. I think during this time when I was sitting at home I thought a lot and also just sitting around caused me to be sick.”***(Participant 007)**

The quotations given below suggest that some individuals attributed their chronic diseases to dietary problems. These individuals indicate that modern foods are different to that in the past and, as a result, more people are likely to get ill.

*“I think it’s the food we eat. In the old days there were no such illnesses and this was because we did not eat these kinds of food. So food may be the cause of these illnesses. We definitely didn’t eat a lot of sugar in those times, maybe some salt but not sugar.”***(Participant 006).**

*“According to the information I got from the nurses, they say that you should be careful of the food you eat. You should not eat too much, but rather eat little bit of food every few hours. Be careful of food that has too much salt or sugar.”***(Participant 007)**

*“Mmmmmmm; I am not so sure but think it’s the food we eat”***(Participant 009)**

*“Chronic illnesses are illnesses caused by the food we eat or sometimes they are due to inheritance.”***(Participant 010)**

Other individuals explained they believe, ranging from genetic inheritance, birth complications and sexual encounters. These participants explained that chronic diseases can be inherited, caused by birth complications or transferred through having sexual intercourse with certain kinds of people (Someone who has just had a miscarriage or abortion). The below mentioned explanations are evidenced in the following quotations:

“Some people it is genetic” (Participant 008)

“High blood I believe was genetic because a lot of people in my family have it” (Participant 010)

“It could be the long delivery I went through when giving birth to her; because this was the first time I ever delivered for that long.”(Participant 005)

“Sex” (Participant 004)

4.3.3 What participants believe are the main cause of their illness (External or internal factors).

Different participants believe in different causes for their illnesses. Some may attribute their illnesses to internal causes such as wrong diet and ways of living; while others believe their illnesses are caused by higher powers, or something external of themselves.

a). Internal attributions:

The underneath participants are of the opinion that chronic diseases are a result of internal factors, meaning that they are caused by an individual unto themselves. These participants believe that our own behaviours (for example, taking in the wrong kinds of foods, thinking or worrying too much, and taking drugs) could exacerbate or lead to chronic diseases.

"I believe we bring these illnesses upon ourselves with the food we eat or thinking too much, illnesses such as high blood we can get when we think too much, or worrying about our children or other things that worry us."(**Participant 001**)

"I have a part to play because if I were to avoid stressful situations and also to eat the food I am told to eat. While taking all the prescribed medication I would not have a problem."(**Participant 002**)

"I think it's the food we eat. In the old days there were no such illnesses and this was because we did not eat these kinds of food. So food may be the cause of these illnesses. We definitely didn't eat a lot of sugar in those times, maybe some salt but not sugar" (**Participant 006**)

"I personally was involved in some accidents when I was younger and I spent some time sitting at home. I think in this time when I was sitting at home I thought a lot and also just sitting around caused me to be sick"(**Participant 007**)

"We have a part: If you smoke weed or drugs your mind will be condemned and you will get sick."(**Participant 010**)

b) External attributions:

Some participants were of the opinion that chronic diseases are external to them; being caused by God, or other people (genetically). One participant mentioned how she thought the illness was from another country and through inter-continent interaction and assimilation it was transferred to South Africa

"It was external of me because I was not born with the illness; it was also passed on to me by someone else."(**Participant 004**)

"At the end of the day it is not up to me, this is Gods choice."(**Participant 005**)

"I think the illness could come from other countries."(**Participant 009**)

4.3.4 Pathways followed by the participants to manage their chronic diseases

From the time an individual is aware that they have a chronic disease, there is a certain amount of discomfort, either physical or psychological that they will experience which prompts them to seeking help. There are certain pathways which an individual will follow to help alleviate or rid themselves of their symptoms. Depending on the magnitude of the discomfort experienced, the nature of the chronic disease and the treatment modality employed, some participants find themselves having to visit various treatment points, before their discomfort could be minimized or completely eradicated. This yields the complex nature of the pathway that these participants follow, highlighting that the path is longer in some cases, depending on the response of the illness/symptoms to the intervention at a specific treatment point, as in the following extracts:

From the quotes below it is evident that some participants have changed their treatment modality. Some who were previously using traditional and spiritual means of management/ treatment have changed. Some participants' state that they changed due to insight that they received concerning their illness, others elaborate that they seized other methods due to unsatisfactory results of the treatment and others complained of financial constraints, and demands made by traditional and spiritual healers that they could not meet.

"Initially I was consulting both Traditionally and Western methods of treatment because I did not know enough about the condition. When she turned four years, I realized that this condition is chronic then I stopped seeking traditional assistance."(**Participant 005**)

"I used to go to my church (ZCC) and get a prescription of what I should drink to assist with my illness. But I noticed that regardless, I was still getting sick, and it was getting worse so I came to the clinic"(**Participant 001**)

"I once tried drinking a certain tea that was being sold in town. When I was making this tea, as it cools down I would realize that it was not tea but it was

coffee. This tea seemed like it also wanted to trouble me, causing me heart palpitations, so I stopped.”(Participant 002)

“Yes, church, they would prescribe for us things to drink and eat but I have stopped for now” “It is far and the transport was costly because I would go there a lot but apart from that they want me to get baptized into the church and I can not do that because I do not want to leave my church of origin.”(Participant 010)

Some participants, like these quoted below, seem to be dependent on dual methods of treatment/ management. These participants report using traditional and spiritual remedies to support or serve as a back-up to the western medication received from the clinics.

“occasionally I drink tea from church but I am told even there (at church) that I should not make it strong.”(Participant 003)

“I went to traditional doctors, their help is different but it also helps” (Participant 006)

Other participants report using dual methods of treatment/ management because the medication received from the clinic does not generate satisfactory results. While others relate that they use both methods because they are unsure which will provide the best results. These participants use the one form of treatment as a protective measure for the other.

“I have been treating this illness through spiritual means. I go to church and receive prescriptions.” “When I drink the medication I get here at the clinic, sometimes I get dizzy but when I use the church one it does not make me dizzy and leaves me feeling better.” (Participant 009)

“ No, I still drink what I am given at church and at the same time I still drink my medication from the clinic. I am drinking both with the hope that it will get better, because you never know what will make you better.” (Participant 001)

From the fore mentioned quotes it is evident that the route of treating or managing, does not always start at other agencies and end up at the health care system, but it can as well start at the health care system. What usually inform the decision to start at the health care system are factors such as the severity of symptoms, initial place of diagnosis or the belief system of the individual sufferer and family members. Further it was evident that whether or not a person remains consulting in the health care system (clinic) is also dependent on the individuals belief system, satisfaction with services and perceived progress of their illness.

4.3.5 Experiences of living with chronic disease

The participants' experiences of living with chronic diseases were explored in relation to their diagnosis and the coping strategies around it. The following comments suggest negative experiences of these participants. These comments seemed to embrace the notion that the chronic disease becomes a negative experience due to the limitations it places upon an individual's life. The above participants elaborate experiencing pain because there are certain previously achievable tasks they were able to do before these chronic diseases and feel restricted and limited by the illness. Others mentioned that they feel restrained by the illness and its requirements (e.g, only having to eat certain kinds of food, or living a certain lifestyle).

“It is painful when you wish you can do some things for yourself but you are not unable to.”(Participant 007)

“I feel pain because I cannot work or market for a job” (Participant 010)

“It has not been good on me because initially they told me about my eyes, that they were having problems due to sugar diabetes and now even sexually I am not able to have an erection.”(Participant 006)

“It only bothers me because now we have to choose what to eat and also to be in constant pain. Sometimes you have body pains (on the knees or in the waist) and when you ask they say it is due to sugar diabetes.”(Participant 001)

“Sometimes I get tired and general body tiredness” (Participant 008)

“It only troubles me because now we have to choose what to eat.”(Participant 002)

The findings of this study further indicate that negative experiences such as fear and worry, can become the aftermath of chronic diseases. Some participants relayed that they find themselves in a state of psychological distress because of their illnesses. They mention fears around symptoms worsening; progression in illness, and even death. Others report experiencing worry because their symptoms are not properly managed.

Below are quotations that suggest not only the negative experiences that the participants have gone through but also the psychological symptoms brought on as consequent of their conditions or the changes brought onto their lives by these conditions. Numerous participants report experiencing different psychological distresses ranging from fear, worry and pain that make it difficult to cope with their diseases.

“It worries me because I am not getting better. I have been taking medication for two years now and I see I am not getting better” (Participant 009)

“Well it is hard; I always fear that the attacks will return.”(Participant 005)

Some participants on the other hand report that their experiences are not too bad, elaborating that they are consoled by the fact that they are not the only ones experiencing what they are experiencing:

“I am not the only person, when we visit the clinic we are a lot all taking the same medication, so I am consoled.”(Participant 003)

Two participants however, report that they have reached a point where they have become accustomed to their conditions. These participants seem to have accepted their condition and are therefore experiencing more positive experiences around their chronic diseases.

“I have been okay, initially I was shy and embarrassed to admit it; but now I am used to the condition.”(Participant 004)

“I have accepted because I know the illness cannot be cured it is just managed.” (Participant 006).

4.3.6 Psychological coping strategies

From the data described in the previous sections, another area to be explored was whether there are psychological strategies employed by these participants to assist them in coping with their chronic diseases. Psychological strategies will be looking into cognitive action, behavioural and emotional ways of coping. Cognitive action may include thought processes, such as positive self-esteem, (e.g. I am more than the illness, I must remain positive). Behaviours can include different life style changes and behavioural adjustments; and emotions include positive feelings around the condition.

Some participants seem to take on a more active role in trying to cope, while others are more passive. Active coping includes such things as accepting the condition, facing their problems head on, collecting information about their illnesses, and regulation of emotions through either maintaining hope or normalizing their symptoms. Passive coping can be described in terms of avoidance, denial, giving up and escaping from the illness.

Indeed some participants demonstrated active coping strategies with some explaining that they have decided to accept their condition, maintain hope, be compliant to medication and live in such a way that will enhance their health.

“Well there is not much that I can do, I take medication as I am told by the doctors and hope for the best.”(Participant 005)

“Firstly I stopped drinking (alcohol); currently I do not drink anymore. I have been unable to stop cigarette though.” (Participant 007)

“Following the doctor’s prescription on medication. Also listening to the foods that they say you should or should not eat. Foods such as salts and sugar must be avoided” (Participant 010).

“I have accepted because I know the illness cannot be cured it is just managed.” (Participant 006)

“So now I just have to accept that I have it and drink my medication.” (Participant 008).

Another active coping strategy that seems to be employed by most participants in this study is changing lifestyle practices. Most participants relay that the best way of managing their chronic diseases and cope with them appropriately is by taking on the correct lifestyle. These lifestyle changes include amongst other things, medication compliance, regular exercise, leading a less stressful lifestyle, stopping alcohol and drug consumption and taking the correct diet for your illness.

“Being careful with the food we eat, excising, and avoiding being constantly worried you will be okay.” (Participant 001)

“Being careful with the food we eat and do not worry too much” (Participant 002)

“Decrease eating food that is not good for the body. (Food with spices, sugar and salts). These medications that they give us are to decrease the illness but we can help ourselves by avoiding wrong foods.” (Participant 006)

“Following the doctor’s prescription on medication. Also listening to the food that they say you should or should not eat. Food such as salts and sugar must be avoided.” (Participant 009)

There are few participants in this study who seem to have taken a more passive coping strategy. These participants sound like they have given up hope and see no progress in their illnesses.

“It’s a constant struggle because I know I will suffer forever, it makes me sad and the worrying is increased but God knows.”(Participant 001)

4.3.7 Receiving lessons or education on the chronic disease.

From the following quotations it was shown that, receiving some kind of insight into an individual’s condition will influence the way they treat, and manage the condition. It will also affect the way in which they view their illness.

“The lessons assisted in letting us know what to eat and what not to eat. They also taught us to exercise, and also avoid fatty food. This assisted us a lot.”(Participant 001)

“The lessons help to give us insight, we are more aware of our illness now and can therefore take better care of ourselves.”(Participant 002)

“The lessons guide us on what to eat and what not to eat, things like fruits and vegetables are good and we must avoid sugar and acidic drinks.”(Participant 006)

“The lessons tell us that we should avoid salts for they close up our veins and to avoid fats. Their teachings are very important.”(Participant 010)

4.4 Summary of findings

The sample was composed of ten (10) participants aged between 11 and 74 years, who are receiving health care services. All the participants are from the local community of Ga-Dikgale and are Sepedi-speaking. The majority of the sample falls under the Christian religion, with a few subscribing to African traditional religion. According to the findings of this study, the participants seem to hold varying perceptions and beliefs in as far as the causes of chronic disease are concerned. These perceptions appear to be individualized, ambiguous and culturally defined. Most participants made use of their own experiences in defining what chronic diseases are, such as the symptoms experienced during the course of the illness.

This study revealed that some participants do not know what chronic diseases are, though they are able to explain their experiences (symptoms, duration etc.) around their disease. It also explored which service providers are visited, and highlighted that whether the participant stays at a specific treatment point, or moves to the next, is determined by factors such as knowledge they have about their illness, recovery and perceived lack of improvement. The path does not always start at other agencies and end up at the health care system, but it can as well start at the health care system. What usually inform the decision to start at the health care system are factors such as the severity of symptoms, initial place of diagnosis or the belief system of the individual sufferer and family members. The services from the health care system appear to be generally positive, and other agencies and providers of care are also consulted while the sufferers receive services from the health care system.

The study further showed that different individuals have different experiences in relation to their illnesses. Some participants reported having negative experiences, while others talked about more neutral to positive experiences. Consequently, these individuals use varying psychological strategies to cope with their conditions. Some participants took on more active roles in coping, while others chose to be more passive.

Lastly this study suggested that those individuals who did receive some form of education about chronic conditions seemed to have more insight into treatment and management of their condition. These individuals seem to have more confidence when it comes to matters related to their illnesses and for this reason seem to do less travelling from one treatment agency to the other and are more compliant with medication.

CHAPTER 5

DISCUSSION OF FINDINGS

5.1 Introduction

This chapter presents and discusses the findings of the study in relation to the literature review and other related information. It also reviews the contribution of the study in terms of the aims set out in Chapter 1. These findings are discussed according to the emerging themes identified in the previous chapter. The findings will also be discussed in terms of their implications for psychological theories on managing chronic diseases.

5.2 Emerging themes

5.2.1 Participants' own explanations of chronic diseases

In the study, participants explained chronic disease mostly in terms of their own personal experiences. Most of the participants in the study were not able to give a clear account of what chronic diseases are, and opted to describe their experiences. The explanations given varied from explanations of the cause, description of symptoms and the demographic explanation of participants with the same illness. The participants were descriptive in saying that because the illness was caused by (dietary intake, genetic composition, sexual behaviour etc.), that is what the illness is; an illness of dietary background or one of genetic composition.

These findings can be summarized by saying that, according to the study there is no universal definition of what is regarded as chronic disease, and the definitions of the disease are ambiguous. Individual participants chose to explain the condition in ways that were specific to themselves. Thus it can be said that individuals opt to individualize the illness. The participants seem to explain the illness in such a way that they have seen it unfold in their lives. Be it an

explanation of the cause, the symptoms, duration of the illness or other phenomenon around the disease.

Most participants in the present study reported a change in lifestyle and mentioned that due to these changes, chronic diseases have begun to be a problem. This is validated by the research study by (Steyn, 2005) showing that the majority of the South African population has moved extensively along the epidemiology transition towards illness profiles that are more related to Western lifestyles. This epidemiological transition is motivated by people adopting unhealthy lifestyles, which relate to tobacco use, unhealthy nutrition, and lack of regular aerobic physical activity.

It was also evident in the study that some people with chronic diseases are moving away from the strictly cultural explanation of their illnesses and depend more on Western notions of the condition. Some participants explained chronic diseases in the same way that these were explained to them by medical staff. Some participants elaborated that upon receiving medication it was explained to them what the condition is and what it entails and they seem to dwell on that as their explanation of the illness. This may be due to the fact that these chronic diseases were initially foreign to African people and therefore there is not vast cultural knowledge on the subject. For this reason it is evident that education and providing knowledge to people with chronic conditions is important in helping them understand and manage their illnesses.

5.2.2 Participants' subjective notions of the events or factors that could have led to their chronic diseases.

The subjective notions of the participants in this study in terms of the events and factors that could have led to their chronic diseases indicate that emotional distress (brought on by everyday stressors, such as death or illness of a loved one, unemployment, family discord etc.), incorrect dietary intake, genetic inheritance, birth complications and sexual encounters were regarded as the

cause of their illnesses. Each specific cause was dependent on the knowledge of the nature of the illness (as learned through health education given at the health care system, or knowledge derived from any other agency consulted), one's belief system and particularly own formulations of what could be the cause. Although these individuals have one thing in common, i.e., suffering from a chronic disease, they have their own unique ways of defining what could be the cause of their illness.

It was evident from the findings that most participants concluded on the factors that have led to their illness based on information they received from health care practitioners or other people in the health care system. These conclusions they form after the diagnoses by the very same health care system. This can be explained by the fact that the illness, was foreign to these individuals prior to diagnoses, and upon diagnoses the individuals seem to have taken all information received to heart.

This lends support to the notion by Madge, (1998 cited in Vaughn, Jacquez, & Barker, 2009), which states that the relationship between cultural attribution and health beliefs then becomes reciprocal and health beliefs form a cognitive schema that influences the way that people make attributions. This would mean that most likely the information that these individuals have received is likely to help them make attributions, and assist them in understanding their disease, and its treatment.

From the above information it is reasonable to conclude that diagnosis is a very important factor in illness knowledge. It is apparent from the study that participants took to heart the information they received from the clinics (place of diagnosis), and can be speculated that if they were diagnosed somewhere else (e.g. traditional healers), that would serve as their reference in conceptualizing and understanding the causes of their illness.

5.2.3 What participants believe are the main causes of their illness (External or internal factors).

From the above findings it is true that different participants believe in different causes. Some attribute their illnesses to internal causes such as wrong diet, emotional distress, and ways of living that include bad habits such as smoking and drinking; while others believe their illnesses are caused by higher powers, or something external of themselves such as a genetic predisposition or God.

The above findings lend support to the view by Peltzer (1995); Torey (1986); Cheetham and Griffith (1982), (Vaughn et al., 2009), Dempster (1982) and Shai,(2012) who all echo the belief that individuals attributions or believes about their chronic diseases are commonly culture specific. In an article by Vaughn, Jacquez, and Barker, (2009) comparison between Weastern and African populations were made in terms of attribution and beliefs. It was evidenced that African patients may be more likely to attribute illness to a spiritual or social causes rather than a physiological or scientific cause.

More related to the above study is the conceptualization of illness according to South African black individuals. According to Dempster (1982), this approach is more complex, including, biological, social, religious, and magical factors as causes of diseases. These factors can be divided into two categories with one including internal causes and the other external.

We can categorize it in such a way as to say that internal causes will include biological and social factors and this is evidenced by participants explaining their diseases to be caused by different factors ranging from self-inflicted disorders brought on by wrong diets, emotional distress, non-compliance to medication and participation in drug and alcohol. While external causes were explained by the participants to include God, genetics and even other individuals, the explanations of these external causes were religious and magical in nature.

In this study it was apparent that most participants attributed their illnesses to internal causes (diet, emotional distress, and drug and alcohol abuse). Regardless of the attribution, some participants still embarked on traditional and religious means of management and treatment.

Interestingly, the present study found that Western and Traditional ways of explaining illnesses seem to be converging. More and more participants seem to be explaining their illnesses in a Western way. This could be explained by the fact that chronic diseases were initially foreign to the African population and that diagnosis seems to be very important in illness knowledge. So since most people are diagnosed with their chronic illnesses in the Western health care system, they use the same notions in explaining their illnesses.

5.2.4 Pathways followed by the participants to manage their chronic disease

In the present study, it was found that most participants have, at one point or another in their illness, consulted other agencies such as traditional healers, faith healers, and private medical doctors for assistance. It does appear that other participants continue to make use of these other healing agencies even though they would have entered the formal (Western) health care system. The reasons behind the use of multiple agencies vary from individual to individual and involve enhancement of the current treatment and serving a protective role.

Marie Modeste and Majeke (2010) conducted a study in Kwazulu-Natal exploring the self-care symptom management strategies used by women living with HIV and AIDS. Their study indicates that a number of different methods of self-care symptom management were reported by the participants. These include medication either prescribed by health care providers after consultation, purchased from a pharmacy, or home remedies. Other symptom management strategies include seeking complementary treatment such as taking traditional medication and spiritual care (Mohaleni, 2013). This was also seen in the current study, with some participants saying that they have been taking other treatment

offered by spiritual or traditional healers in order to complement or enhance the treatment they are receiving from the clinic.

Previous studies conducted have shown that African people will simultaneously access the services of Western and traditional healers for the same symptoms based on the cultural conception that an illness is both physical and spiritual (Berg, 2003 as cited in Shai, 2012). Similarly, in the present study, it was found that some participants continued to receive traditional or spiritual remedies whilst they were on medication from the local clinics.

Some participants mention that they were seeking both Traditional and Western methods of management because of their lack of knowledge. However, once they received insight they stopped using the traditional remedies. Burman (1996) puts emphasis on factors such as health knowledge, cultural background and socio-demographic characteristics to determine management strategies of different individuals. Health knowledge is one of the significant factors determining the help-seeking pathways taken. Focusing on the influence of health knowledge, Howell, Smith, and Roman, (2008) conducted a study among patients diagnosed with lymphoma in West Yorkshire, examining their beliefs and actions about help seeking. They found that a lack of knowledge and the interpretation of symptoms as not being serious led to delays in help-seeking. Not only does lack or shortage of health knowledge lead to delay in seeking help, but also causes the individual to seek more methods of help. One individual may travel from one assisting agency to the other, looking for something that will provide satisfactory results or a cure. Once the individual receives information that their illness is chronic and that there is no cure, they are more likely to settle for one method of management.

Interestingly, the findings show that the path does not always start at other agencies and end up at the health care system, but may as well start at the health care system. In that case, the decision to start at the health care system appears to be informed by factors such as the severity of the symptoms, initial place of diagnosis, and progress in treatment. According to Shai (2012), In South

Africa it has been indicated by some studies that the nature of how the illness is perceived appears complex, thus making help-seeking pathways not to be predictable and linear. These pathways may include back and forward movement between western and traditional health care systems. Holdstock (2000) postulates that people from African background use both Western and Traditional health simultaneously because they are perceived to be complementary and as targeting different aspects of the illness.

5.2.5 Experiences of living with chronic diseases

Philips and Rachman (1996) argue that once a problem becomes chronic, psychological factors increasingly become important in its understanding and management. According to Sarafino, (1994) studies have shown that psychological and biological systems are interrelated, that is, as one system changes, the others are often affected. Depression, feelings of frustration, confusion, anger about the illness, and a sense of being out of control are some of the most frequent emotional effects of being diagnosed with a chronic condition (Smith, Harre, & Langenhoven, 1995). Individuals can also be affected by stigmatization that stems from the disorder, fear of being labelled or diagnosed and the fear of transmission or progression of the disorder.

In the current study, the participants' experiences of living with chronic disease were explored in relation to their lives post diagnosis. Most participants complained that living with a chronic disease had not been a pleasant experience, and that it brought on increased emotional distress and pain in the form of feelings of incapability and limitation (limitations with relation to physical activity, cognitive activities and other capabilities), feelings of hopelessness and helplessness, worry and fear. They mentioned that they fear that symptoms might worsen or they might end up dead. Others report experiencing worry because their symptoms are not properly managed. Individuals with chronic

health conditions are at great risk of emotional distress, behavioural problems, as well as social difficulties (Ross et al. 2009). Some participants reported that most of their negative experiences around their illnesses were due to the physical pain they suffer.

Alternatively other participants seemed to have taken a more positive stance in relation to life post diagnosis. Some relay that they are consoled by the fact that they are not the only individuals suffering from the condition. While others say that since it is a chronic disease they find that it is easier to accept and continue living. This fact is similar to that explained by the theory of universality employed many a times in group therapy. This theory focuses mainly on the recognition of shared experiences and feelings among group members and that these may be widespread or universal human concerns. These shared experiences then serve to remove a group member's sense of isolation, validate their experiences, and raise self-esteem. This seems to be the case with some of the participants in the study; because they know that they are not the only ones with these illnesses this has helped them live better and untimely accept their conditions.

5.2.6 Psychological coping strategies

According to Bussing et al.,(2012), there are different ways to cope with a chronic disease; with the most common being passive and active coping. Active coping encompasses problem solving; collecting information and refocusing on the problem, or regulating emotions by focusing attention on the emotional response aroused by the stressor. These methods are likely to lead to less pain, less depression, less functional impairment, and higher general self-efficacy, while passive coping (i.e., avoidance and escape) is correlated with reports of greater depression, greater pain and flare-up activity, greater functional impairment, and lower general self-efficacy.

Some participants in the study seem to have taken on an active role in coping with their chronic diseases. These individuals have participated in actions such

as accepting their condition, facing their problems head on, collecting information about their illnesses, and regulation of emotions through either maintaining hope or normalizing their symptoms. Another active coping strategy that seems to be employed by most participants in this study is positive lifestyle change. Most participants relay that the best way of managing their chronic diseases and cope with them appropriately is by taking on the correct lifestyle. These lifestyle changes include amongst other things, medication compliance, regular exercises, stopping alcohol and drug consumption and eating the correct diet for your illness. This action of changing lifestyle practices is one echoed in many articles, journals, and books. It is also supported by many health care workers, who advice that proper management and coping with chronic diseases includes positive life style transformation and adjustment.

Some participants have made the decision to be passive about their illness, and seem to be having a hard time coping. These individuals are not coping because they have chosen to either, avoid, deny, or giving up hope and escaping from the illness. This not only increases the burden of the disease but also its psychological consequences (Bussing et al., 2012).

5.3 Implications for theory

According to the attribution theory, different individuals from diverse cultural backgrounds attribute their diseases to different things and for this reason have different ways of looking or dealing with their illnesses. Some participants attributed their illnesses to self-inflicted changes such as wrong diet, emotional distress, sexual behaviour and drug and alcohol use, and for this reason their main form of management was to alter these wrong behaviours, while complying with medication. Even those participants who believed their illnesses were caused by a higher power still seemed to try their own methods of management such methods as medication compliance and a change in lifestyle.

Contrary to the literature above that mentions that “The personalistic (about human, witch, sorcerer, non-human, or supernatural force) and emotionalistic (emotional matters) illness theories; are easily applied to patients of non-Western cultural backgrounds who are familiar with and have faith in the medical beliefs and practices from their own cultures (Foster, 1974). Participants in this study demonstrated more naturalistic attributional styles. Naturalistic illness theories explain illness in objective, scientific terms and have the core concept that illness occurs when the body is out of balance.

5.4 Summary

In this chapter the findings of the study were presented. The findings were outlined under the following headings: Participants own explanations of chronic diseases, participants subjective notion of factors that could have led to their chronic diseases, what participants believe are the main causes of their illness, pathways followed by the participants to manage their chronic diseases, experiences of living with chronic diseases and psychological coping strategies. A further account of the theory used in the study and its implication was presented.

CHAPTER 6

SUMMARY AND CONCLUSION

6.1 Summary

This study investigated the psychological strategies used by people in Ga-Dikgale community to manage chronic diseases. Individuals suffering from chronic diseases were given the opportunity to talk about their subjective experiences in relation to their conditions. The study suggests that causal explanations and perceptions about chronic diseases are individualistic and culturally-rooted. The individualistic nature of the explanations makes them ambiguous. It was discovered in the study that, diagnosis served as an important aspect in illness knowledge. Many participants explained that they place of diagnosis and the education received at that place served as imperative in them understanding their chronic conditions.

In managing their chronic diseases the study revealed that most participants believe that it is important to adopt a healthy lifestyle in order to manage the illness. This change in lifestyle may include many objectives such as; food choices, sports activities, drug and alcohol use, positive mental action, psychological wellness and medication compliance.

The study also found that various agencies and providers of health care are visited by individuals suffering from chronic diseases, and that the path appears to vary according to the individual's belief system, knowledge about the illness, nature of the symptoms, and progress of treatment. In the study it was evident that perceived lack of improvement by either the patient or his/her family served as an impetus for them to move to the next treatment point. Staying at one point was associated with some form of alleviation of the symptoms or distress. The findings also revealed that there is a dual/multiple use of services, i.e., Western and African, and that the sufferers' general experiences about the services provided by the mental health care facility appear generally positive.

6.2 Limitations of the study

The researcher is aware of the limitations of this study. Firstly, translating the interview data from Sepedi into English might have led to omissions or inappropriate substitutions of the original material provided by the participants. Secondly, this study relied only on the patients' subjective experiences and perceptions of their illness and the management strategies used in order to ease their distress. Other people (for example, their significant others) were not interviewed and as such, the present study gave a one-sided interpretation of the phenomenon. Thirdly, the present study did not tap into other areas such as the experiences and perceptions of health care providers about the phenomenon under discussion. Lastly, the results of this study cannot be generalized to the larger South African population since the study was conducted on a small sample of participants at Ga-Dikgale community.

6.3 Contributions and recommendations

The researcher is of the view that the current study has made a contribution to the literature on chronic disease by providing a qualitative insight into the psychological management strategies followed by health care users post diagnosis. Specifically:

- The findings of the current study have shed some light into areas that may require further research. Such future studies should involve larger and more representative samples that would enable generalizability of the findings.
- The findings have also placed emphasis on the individual and not just the disease they are suffering from or the system in which they are in.
- The findings have placed further emphasis on patients' own role in managing their diseases.
- The findings have also increased literature on the subject of chronic disease management.

Based on the above, the following recommendations are made:

- A comprehensive view of chronic diseases requires a holistic and integrated approach that can cater for both the psychological and medical elements of the distress.
- Policy makers should understand that irrespective of the social, political and economic changes in the country, culture still forms the basis for subjective experience of distress.
- It would be beneficial to include communities and consumers in the development and implementation of health policies. This could possibly lead to culturally-appropriate health care services that have been tailored to people's needs and are better used.
- It is also recommended that the issue of psychosocial rehabilitation be looked into and addressed. This is a comprehensive process that will offer individuals who are impaired, disabled or handicapped by a chronic disease to reach their optimal level of independent functioning in the community.

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APPENDICES

Appendix 1(a): Interview guide in English

1. As an individual who has a chronic disease, I would like you to share with me according to your own understanding of events and factors that could have led to your illness.
2. I would also like you to explain, according to your own understanding, cultural beliefs and experiences of what chronic diseases are.
3. Since you were diagnosed with the chronic disease you have, in what way have you managed it?
4. What other agencies and providers of health care are you using currently, whilst you are receiving services from the mental health care system?

Appendix 1 (b): Interview guide in Sepedi

1. Bjalo ka motho yo a nago le bolwetši bja go se alafege, Ke rata ge o ka nhlalosešša goya ka kwišišo ya gago dilo tšeo di dirilego gore o swarwe ke bolwetši bjo.
2. Nka rata gape ge o ka nhlalosešša go ya ka kwišišo ya gago, tumelo ya gago, le maitemogelo mabapi le malwetši ao a sa alafegego.
3. Sale o boditšwe gore o swerwe ke bolwetši bjo bja go se alafege, o likile bjang go bo hlokomela?
4. Ke mafelo afe ao a go thušago mabapi le bolwetši bjo bja gago, ntle le bookelo

Appendix 2 (a): Participant consent letter and form

Department of Psychology

University of Limpopo (Turfloop Campus)

Private Bag X1106

Sovenga

0727

Date _____

Dear Participant

Thank you for showing interest in this study that focuses on Psychological strategies used by people in the Ga-Dikgale community to manage chronic diseases.

This study will mainly be focused on individuals from the Ga-Dikgale community who have been diagnosed with chronic diseases. The purpose of this study is to explore cultural health attributions, including beliefs about the chronic conditions and psychological coping strategies that people with chronic diseases at Ga-Dikgale community utilize to manage their conditions.

Your responses to this interview will remain strictly confidential. The researcher will attempt not to identify you with the responses you gave during the interview or disclose your name as a participant in the study. Please be advised that your participation in this study is voluntary and that you have the right to terminate your participation at any time.

Kindly answer all the questions as truthfully as possible. Your participation in this research is very important. Thank you for your time.

Yours Sincerely

.....

MoederShimaKhwinana (Student)

Date

.....

.....

Prof. T. Sodi (Supervisor)

Date

.....

.....

Mr Nkoana S.E (Co- Supervisor)

Date

Appendix 2 (b): Participant consent letter and form in Sepedi

Department of Psychology
University of Limpopo (Turfloop Campus)
Private Bag X1106
Sovenga
0727

Letšatšikgweri _____

Thobela Motšeakarolo

Ke leboga go bontšha kgahlego ga lena mo go nyakišišo ye e lebeletšego mekgwa ya di tshekatsheko tša menagano go malwetši a go se alafege. Re lebeletše kudu mekgwa yeo badudi ba motse wa Ga-Dikgale ba hlokomelago malwetši ao.

Nyakišišo ye e tlo lebelela fela badudi ba motse wa Ga-Dikgale, bao ba boditšwego gore baswerwe ke malwetši a go se alafege. Maikemišetšo a nyakišišo ye ke go nyaka go kwešiša di tumelo tša setšo le gore batho ba kgolwa gore malwetši ao a hlokang kalafo a hlolwa ke eng. Malwetši ba ba šomiša mekgwa efe go hlokomela malwetši ao.

Dikarabo tša lena go dipotšišo tše, di tla swarwa ka mokgwa wa sephiri.

Monyakišiši o tla leka ka mešegofela gore a seke a le amanya le dikarabo tše le tla di fago, le ge ele go se utulle leina la lena bjalo ka motšeakarolo lesolong le.

Le tsebišwa gore go tšea karolo ga lena go lesolo le go dirwa ka boithaopo, le gore le nale tokelo ya go ikgogela morago nako efe goba efe. 68

Le kgopelwa go araba dipotšišo tše ka botshephegi bjo bogolo. Go tšea karolo ga lena go lesolo le, go bohlokwa kudu. Ke leboga nako ya lena.

Wa lena

.....

Khwinana Moeder Shima
(Masters Student)

.....

Prof. T. Sodi
(Supervisor)

.....

Mr Nkoana S.E.
(Co-Supervisor)

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Letšatšikgwedi

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Letšatšikgwedi

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Letšatšikgwedi

Appendix 3 (a): Consent form to be signed by the participant

I Hereby agree to participate in this master's research project that focuses on exploring cultural health attributions, including beliefs about the chronic conditions and psychological coping strategies that people with chronic diseases at Ga-Dikgale community utilize to manage their conditions.

I understand that I am participating without being forced. I also understand that I can terminate my participation in this study at any point should I wish to do so; and this decision will not affect me negatively in any way.

I understand that the purpose of this research is not to benefit me personally. Also understanding that all my information on this form and answer sheet will be kept confidential.

.....

.....

Signature

Date

Appendix 3 (b): Consent form to be signed by the participant in Sepedi

Foromo ya tumelano

Nna _____ ke dumela go tšea karolo go lesolo la go nyakišiša tša tshepedišo ya maphelo goya ka setšo le ditumelo, mabapi le malwetši a go hloka kalafi. Lesolo le ke la go nyakišiša gore rekgona bjang go phela ka malwetši a a go hloka kalafi, le gore a re ama bjang megopolong ya rena.

Ke hlaloseditšwe ka maikemišetšo a lesolo le, ebile ke kwešiša gore ke tšea karolo ka go ithaopa, ntle le go gapeletšwa. Ke kwešiša gore nka ikogela morago nako efe le efe ge nka kwa ke sa nyake go tšwela pele, le gore kgato yeo e ka se nkame ga mpe.

Ke kwešiša gore maikemišetšo a lesolo le ga se go ithuša ka bolwetši bjo. Leina la ka le ge e ka ba ditaba tše di filwego ke nna di ka se utullwe (di tla šireletšwa).

.....

.....

Signature

Letšatšikgwedi

Appendix 4: Interview Transcripts

Participant 001 (Ga-Dikgale Clinic)

Age and gender: 74 year old Female

Diagnosis of patient: Both Sugar diabetes and high blood pressure

Time period of patient's condition? On treatment since 2008

Religious belief: Christian Z.C.C

Recording from the Interview

1. I would like you to explain, according to your own understanding, cultural beliefs and experiences what chronic diseases are?

- *Chronic diseases are illnesses caused by old age or food that we eat. These days we do not eat like we did back in time, now we eat foods that have spices and fats. Even in food such as cabbage and rice we put in oils and just eat and this is not good for us, especially we older people. I personally do not like things that have fat anymore, things such as fat cakes or pumpkin, especially when it has sugar.*

2. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?

- I believe we bring these illnesses upon ourselves with the food we eat or thinking too much, illnesses such as high blood we can get when we think too much, or worrying about our children or other things that worry us.

3. As an individual who has a chronic disease, I would like you to share with me according to your own understanding of events and factors that could have led to your illness?

- I do not know, especially because even at the times I was giving birth I gave birth properly at 9months and my periods also stopped themselves properly, so I do not know the cause of my illness.

4. When did you find out about your illness?

- I have known for five years, I was not feeling too well and when I went to the hospital they informed me that I have high blood pressure and sugar diabetes and I started on medication. Now I am on the needle because recently they said the pills are not able to properly manage my illness.

5. From when you found out about your illness, were there other methods in which you were seeking assistance with your illness?

- I used to go to my church (ZCC) and get a prescription to what I should drink to assist with my illness. But I noticed that regardless, I was still getting sick, and it was getting worse so I came to the clinic.

6. So now currently, what other agencies or providers of health care are you using, while receiving treatment from your local clinic?

- No, I still drink what I am given at church and at the same time I still drink my medication from the clinic. I am drinking both with the hope that it will get better, because you never know what will make you better.

7. From the time you found out about your illness, how have you been coping with or feeling about it?

- It only bothers me because now we have to choose what to eat and also to be in constant pain. Sometimes you have body pains (on the knees or in the waist) and when you ask they say it is due to sugar diabetes.

8. Since you know that the illness is chronic and will not get cured, how have you been coping with that?

- It's a constant struggle because I know I will suffer forever, it makes me sad and the worrying is increased but GOD knows.

9. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- I have been to numerous places; here at the clinic they gave us some information. I have also gone to Mamelodi where they were opening a clinic especially for individuals with chronic diseases and there we were given lessons.

10. What impact do you feel these lessons had?

- They assisted in letting us know what to eat and what not to eat. They also taught us to exercise, and also avoid fatty food. This assisted us a lot.

11. What form of assistance do you deem best for a person in your condition?

- Being careful with the food we eat, exercising, and avoiding being constantly worried you will be okay.

Participant 002

Age and Gender: 64 year old Female

Diagnosis of Patient: High blood pressure and Sugar diabetes

Time period of patient's condition: High blood pressure since 1999 and Sugar diabetes since 2002

Religious belief: Christian (Nazarene)

Recording from the Interview

1. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?

- I believe that these conditions stem from stress or thinking too much. I remember that my sibling passed away while I was already diagnosed and when that happened I was admitted in Mankweng hospital due to the fact that my sugar was around 24.8, because I was hurt and therefore I was under stress.

2. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?

- I have a part to play because if I were to avoid stressful situations and also to eat the foods I am told to eat. While taking all the prescribed medication I would not have a problem.

3. Do you believe that there is in some way that you caused this illness?

- Yes I think it's the food that I ate and also thinking too much.

- 4. I would also like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?**
- I do not know.
- 5. How are we supposed to maintain our health, even with these Chronic illnesses?**
- Through being obedient to the doctor's prescription into what you should eat and what not to eat. If you respect these prescriptions you are likely to live longer.
- 6. Since you were diagnosed with the chronic disease you have, in what way have you managed it?**
- I just went to the clinic in 1999 and this is where I received my assistance.
- 7. Because you know that the illness is chronic and will not be cured, how have you been coping with this?**
- There is nothing I can do about that, all I can do is accept and try to be obedient to the doctors' instructions.
- 8. What other agencies and providers of health care are you using currently, whilst you are receiving services from the mental health care system?**
- No: I do not drink traditional medication, I trust the western medication. I once tried drinking a certain tea that was being sold in town. When I was making this tea, as it cools down I would realize that it was not tea but it was coffee. This tea seemed like it also wanted to trouble me, causing me heart palpitations. My daughter also sells medications for such illnesses (herbal something) that I have but I will not take it until I die. I will only take my pills for high blood and sugar diabetes.

9. From the time you found out about your illness, how have you been coping with or feeling about it?

- It only troubles me because now we have to choose what to eat. But I can say that now I am used to it.

10. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- Yes, sometimes at the clinic we are given some information about our illnesses.

11. What impact do you feel these lessons had?

- They help to give us insight, we are more aware of our illness now and can therefore take better care of ourselves.

12. What form of assistance do you deem best for a person in your condition?

- Being careful with the food we eat and do not worry too much.

Participant 003

Age: 58 year old Female

Diagnosis of Patient: High blood pressure

Time period of patient's condition: High blood pressure since 2008

Religious belief: Christian (Z.C.C)

Recording from the Interview

- 1. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?**
 - Problems that bother a person, causing them to constantly talk to themselves and worry.

- 2. I would also like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?**
 - I would lie, I do not know.

- 3. What is the chronic disease that you are suffering from?**
 - High blood pressure.

- 4. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?**
 - I do not know really, maybe both. I know that worrying a lot may bring on the illness but really it must also have a reason why it came.

- 5. What do you think that reason is?**
 - I do not know.

- 6. From the time you found out about your illness, how have you been coping with or feeling about it?**
 - I am not the only person, when we visit the clinic we are a lot all taking the same medication, so I am consoled.

7. How do you feel about the fact that it is chronic and that you will have to be on medication forever?

- As I mentioned before, I am not the only one with the condition. People are going on with their daily lives regardless of the illness so I can do the same.

8. Since you were diagnosed with the chronic disease you have, in what way have you managed it?

- By taking the medication from the clinic.

9. What other agencies and providers of health care are you using currently, whilst you are receiving services from the mental health care system?

- None, occasionally I drink tea from church but I am told even there (at church) that I should not make it strong.

10. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- No.

Participant 004

Age: 37 Year old Female

Diagnosis of Patient: HIV/ AIDS

Time period of patient's condition: Patient was diagnosed in 2008 and is not currently on any treatment.

Religious belief: Not Available

Recording from the Interview

- 1. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?**
 - Sex.

- 2. I would also like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?**
 - If you sleep with someone who has lost their child (miscarried or abortion), you will get a condition called Makgoma.

- 3. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?**
 - It was external of me because I was not born with the illness, It was also passed on to me by someone else.

- 4. How are we suppose to maintain our health, even with these Chronic illnesses?**
 - Condomising, Condomize and avoid stress.

- 5. Since you were diagnosed with the chronic disease you have, in what way have you managed it?**
 - Nothing, I am just living with no assistance. Though when I was pregnant I used to drink medication to help protect my child.

- 6. What other agencies and providers of health care are you using currently?**
 - No other places.

7. From the time you found out about your illness, how have you been coping with or feeling about it?

- I have been okay, initially I was shy and embarrassed to admit it; but now I am used to the condition.

8. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- No.

Participant 005

Age: 11 year (mother 45 years) Female

Diagnosis of Patient: Epilepsy

Time period of patient's condition: Since birth

Religious belief: Born Again Christian

Recording from the Interview

1. As an individual with a child who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to the illness?

- The child took a long time to breathe and get oxygen and that's how the condition came about.

2. Do you think this is the only reason for this condition or any other reason?

- It could be the long delivery I went through when giving birth to her; because this was the first time I ever delivered for that long.

- 3. I would also like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?**
 - I do not know, because it's the first time I come across this illness.

- 4. Since she was diagnosed with the chronic disease, in what way have you managed it?**
 - I was going to the clinic for medication , she has been on medication since birth due to the fits.

- 5. What other agencies and providers of health care are you using currently?**
 - Initially I was consulting both Traditionally and Western treatment agencies because I did not know enough about the condition. When she turned four years, I realized that this condition is chronic then I stopped seeking traditional assistance.

- 6. What form of assistance were you receiving traditionally?**
 - They said the child was bewitched and they would give us things to drink.

- 7. Do you believe you have a part to play in the child's illness or that the cause of the illness is external of you?**
 - Since I am the child's mother, there are times where I blame myself for this illness. Though at the end of the day it is not up to me, this is Gods choice.

- 8. From the time you found out about your illness, how have you been coping with or feeling about it?**
 - Well it is hard; I always fear that the attacks will return.

9. Since you know that the condition is chronic, how do you feel about it and how do you deal with it?

- Well there is not much that I can do, I take medication as I am told by the doctors and hope for the best.

10. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- No.

Participant 006 (Ga-Dikgale Clinic)

Age and Gender: 64 year old Male

Diagnosis of Patient: High blood pressure and sugar diabetes

Time period of patients condition: On medication since 2001/2002

Religious belief: Traditional

Recording from the Interview

1. I would like you to explain, according to your own understanding, cultural beliefs and experiences what chronic diseases are?

- I do not know exactly but I have heard that it is caused by foods that contain too much sugar or too much salt.

2. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?

- *I think it's the food we eat. In the old days there were no such illnesses and this was because we did not eat these kinds of food. So food may be*

the cause of these illnesses. We definitely didn't eat a lot of sugar in those times, maybe some salt but not sugar.

3. Looking into how these conditions are caused, how do you think an individual can avoid or maintain these illnesses?

- Decrease eating foods that are not good for the body. (Foods with spices, sugar and salts). These medications that they give us are to decrease the illness but we can help ourselves by avoiding wrong foods.

4. From the time you found out about your illness, how have you been coping with or feeling about it?

- *It has not been good on me because initially they told me about my eyes that they were having problems due to sugar diabetes and now even sexually I am not able to have an erection.*

5. From the time you found out about your illness, how have you been coping with or feeling about it?

- I have accepted because I know the illness can not be cured it is just managed.

6. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- I got lessons here at the clinic about what to eat and what not to eat.

7. How have the lessons assisted?

- They guide us on what to eat and what no to eat, things like fruits and *vegetables* are good and we must avoid sugars and acidic drinks.

8. What other agencies and providers of health care are you using currently?

- When I was still working I was going to private doctors to try and get assistance and yes they were helping a lot.

9. Besides medical assistance, what kind of assistance did you get?

- I went to traditional doctors, their help is different but it also helps.

10. Currently are you consulting anywhere else besides here at the clinic

- NO: These traditional people are sometimes costly so this is the reason I stopped going there and opted for the clinics treatment.

Participant 007 (Ga- Dikgale Clinic)

Age and Gender:71 year old male

Diagnosis of patient: High blood pressure and sugar diabetes

Time period of patients condition: On medication since 2003

Religious belief: Not Available

Recording from the Interview

1. I would like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?

- *These are conditions in which one will continue drinking medication forever. If you stop the medication you will die.*

- 2. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?**
- *According to the information I got from the nurses, they say that you should be careful of the food you eat. You should not eat too much, but rather eat little bit of food every few hours. Be careful of food that has too much salt or sugar.*
- 3. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?**
- I personally was involved in some accidents when I was younger and I spent some time sitting at home. I think in this time when I was sitting at home I thought a lot and also just sitting around caused me to be sick.
- 4. So according to you, you believe that your illness was caused by you sitting at home thinking too much or not having anything to do?**
- Yes, sitting at home with no form of income and thinking a lot about that will make a person sick. At times there are things you want that you can not get because you are unemployed and this will complicate a person's condition. This constant thinking is the one that creates the condition.
- 5. From the time you found out about your illness, how have you been coping with or feeling about it?**
- Initially my high blood pressure was very high and a certain nurse referred me to the clinic, once I begun on medication I feel better. It is painful when you wish you can do some things for yourself but you are unable to. Because it is something that is continuously on your mind the condition will just get worse.

6. How do you cope with the fact that it is a chronic illness, and that it will not be cured?

- It is painful when you wish you can do some things for yourself but you are not unable to. Because it is something that is continuously on your mind the condition will just get worse.

7. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?

- No: I just personally thought of the causes. No one came and formally educated me.

8. Since you were diagnosed with the chronic disease you have, in what way have you managed it?

- Firstly I stopped drinking; currently I do not drink anymore. I have been unable to stop cigarette though. I think too much and when I think I need to smoke.

9. What other agencies and providers of health care have you ever tried?

- None: When I looked at the medication I was getting at the clinic I saw that they were helping and I was satisfied. Besides I will not always have money to go consult with other doctors.

10. Besides other doctors, maybe traditional or spiritual assistance?

- None: I do not go to church and I also do not believe that another individual will tell me better than I already know about my own body.

PARTICIPANT 008 (Ga- Dikgale Clinic)

Age and Gender: 32 year old male

Diagnosis of patient: Schizophrenic patient

Time period of patients condition: On medication for four years

Religious belief: Not Available

Recording from the Interview

- 1. I would also you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?**
 - I do not know.

- 2. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?**
 - I was once assaulted and spent a month in hospital that led to this illness.

- 3. Looking at other people who may have the same illness but were not assaulted, do you think they had a part to play in them getting the illness or do you think it was external of them?**
 - Some people it is genetic.

- 4. From the time you found out about your illness, how have you been coping with or feeling about it?**
 - Sometimes I get tired and general body tiredness.

- 5. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?**
 - No.

- 6. Since you were diagnosed with the chronic disease you have, in what way have you managed it?**
 - Nothing, just medication.

7. How do you feel and handle the fact that your illness is chronic and that it will not be cured?

- I am not happy because I know that I was not born with the illness, so now I just have to accept that I have it and drink my medication.

8. What other agencies and providers of health care have you ever tried?

- None

Participant 009 (Ga- Dikgale Clinic)

Age and Gender: 68 year old male

Diagnosis of patient: High blood pressure

Time period of patients condition: Been diagnosed for two years and is on medication.

Religious belief: Christian Z.C.C.

Recording from the Interview

1. I would like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?

- I do not know.

2. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?

- Mmmmmmm I am not so sure but think it's the food we eat.

- 3. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?**
 - I think the illness could come from other countries.

- 4. From the time you found out about your illness, how have you been coping with or feeling about it?**
 - It worries me because I am not getting better. I have been taking medication for two years now and I see I am not getting better.

- 5. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?**
 - No.

- 6. Since you were diagnosed with the chronic disease you have, in what way have you managed it?**
 - I have been treating this illness through spiritual means. I go to church and receive prescriptions.

- 7. How much has it helped?**
 - I have observed that it helps very much.

- 8. How?**
 - When I drink the medication I get here at the clinic, sometimes I get dizzy but when I use the church one it does not make me dizzy and leaves me feeling better.

Participant 010 (Ga- Dikgale Clinic)

Age and Gender: 31 year old male

Diagnosis of patient: High blood pressure and schizophrenia (Delusions)

Time period of patients condition: 6 years on medication for both

Religious belief: Christian (Lutheran) yet consulting at Z.C.C church

Recording from the Interview

1. I would like you to explain, according to your own understanding, cultural beliefs and experience what chronic diseases are?

- Chronic illnesses are illnesses caused by the food we eat or sometimes they are due to inheritance.

2. As an individual who has a chronic disease, I would like you to share with me according to your understanding of events and factors that could have led to your illness?

- High blood I believe was genetic because a lot of people in my family have it, but the other I do not know.

3. Do you believe you have a part to play in the illness you have or that the cause of the illness is external of you?

- We have a part: If you smoke weed or drugs you mind will be condemned and you will get sick.

- 4. Looking at the condition of which you have (High blood) do you believe a person has a part they play?**
 - Yes the food, the food we eat now is not the same as what was eaten in the past. Some foods fight against the purpose of the medication we take.

- 5. Since you were diagnosed with the chronic disease you have, in what way have you managed it?**
 - Following the doctor's prescription on medication. Also listening to the foods that they say you should or should not eat. Foods such as salts and sugar must be avoided.

- 6. From the time you found out about your illness, how have you been coping with or feeling about it?**
 - I feel pain because I cannot work or market for a job.

- 7. Have you ever been given lessons or education on your illnesses? Have you ever researched about your condition?**
 - Occasionally dieticians come and teach us.

- 8. What difference do the teachings make?**
 - They tell us that we should avoid salts for they close up our veins and to avoid fats. Their teachings are very important.

- 9. What other agencies and providers of health care have you ever tried?**
 - Yes church, they would prescribe for us things to drink and eat but I have stopped for now.

- 10. What is the reason for you stopping?**
 - It is far and the transport was costly because I would go there a lot but apart from that they want me to get baptized into the church and I cannot do that because I do not want to leave my church of origin.

