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THE EXPLORATION OF THE PSYCHOLOGICAL WELL-BEING OF PEOPLE LIVING WITH HIV/AIDS (PLWHA) IN LUSIKISIKI, IN THE EASTERN CAPE, SOUTH AFRICA

BY

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A dissertation in fulfilment for the requirement for the degree of Social Sciences (Psychology) Masters by Dissertation

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DECLARATION

I, Nombulelo Nodwengu, hereby submit this written declaration on the foundation that this research was conducted by me, submitted as it fulfils the requirements to complete the Masters in Psychology in the Faculty of Social Science and Humanities at the University of Fort Hare in 2019. I declare that this research is my own, the work has not been submitted anywhere before for any Degree or examination purpose in any other institution. I also declare that all sources that I have used have been acknowledged.

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Nodwengu, N   Date

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DEDICATION

I would like to dedicate this study to my younger sister who has always been my pillar of strength through the years I have been studying, supporting me and my children financially and without her support I would not have made it this far. She has been like a parent in the absence of our parents for me, I appreciate her so much. I would also like to dedicate this study to all the people who assisted me most, especially the community of Lusikisiki, in the Eastern Cape, South Africa more particularly, people living with HIV/AIDS because without their cooperation and assistance this study, it would not have been a success.

ABSTRACT

The study explored the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape, South Africa. The aim was to describe how they cope physically, socially and psychologically in their everyday lives as they deal with the consequences of stress while living with HIV. The researcher employed exploratory qualitative research. Fifteen participants from one of the support groups under the supervision of the Treatment Action Campaign (TAC) District office in Lusikisiki, in the Eastern Cape, consisting of seven males and eight females, aged from 20-60 gave their consent to be interviewed.

The majority of the participants depended on the child support grant while others were doing part-time jobs in order to make a living. These results demonstrated that PLWHA are doing well in terms of accepting their HIV-positive status, accessing treatment and getting support. They use self-motivation, spirituality or religion and support groups as coping strategies. However, unemployment still plays a primary role in the psychological well-being of PLWHA in Lusikisiki as people lack means to make ends meet which results in them constantly being in a state of turmoil, stressing about where their next meal will come from thus influencing negatively on their quality of life. It is recommended that community projects such as growing chickens and planting vegetables in gardens for generating income and for their own consumption could assist in making the lives of PLWHA better if there could be funders who would be willing to sponsor such projects.

Key words: *People living with HIV/AIDS; Antiretroviral Therapy (ART); Psychological well-being; unemployment*

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
NGO	Non-governmental Organization
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-Exposure Prophylaxis
TAC	Treatment Action Campaign
WHO	World Health Organization
UNAIDS	Joint Union Nations Programme on HIV/AIDS

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CHAPTER 1: INTRODUCTION

According to the World Health Organization (WHO) (2014), HIV is the virus that causes AIDS and it continues to be a major global health issue. Globally, about 12.9 million people living with HIV/AIDS (PLWHA) were receiving Antiretroviral Therapy (ART) by the end of 2013 and 11.7 million of them were in low- and middle-income countries. ART involves a combination of HIV medicines to be taken on a daily basis. It was stated that the target of placing 15 million PLWHA on ART in these countries by looking at the way ART provision had been accelerated, was to be exceeded by 2015. This was evident in 2013 when an additional 2 million PLWHA started receiving ART, which was marked as the largest ever annual increase in ART provision. It was further stated that the number of people dying from HIV-related causes per year had decreased by 25% in recent years (WHO, 2014).

In 2014, Joint Union Nations Programme on HIV/AIDS (UNAIDS) boldly announced new targets for the global response to HIV (90% of all people who are HIV-positive being diagnosed, 90% of those diagnosed be provided with treatment and 90% of PLWHA on treatment achieving an undetectable viral load) by 2020 (UNAIDS, 2014). A partnership between the affected communities together with health services, government and researches have been identified as the force behind these effective responses to HIV (Brown, O'Donell, Crooks & Lake, 2014). There are behavioural interventions, which are also aimed at achieving changes in individual behaviour such as the use of condoms and safe injecting equipment, regular HIV testing, and uptake of treatment (for prevention or health management).

These include interventions such as peer education, community outreach, counseling and social marketing (Mwale, 2016).

In a study conducted in China Sun, Wu, Qu, Lu and Wang (2014) reported that PLWHA suffer from serious psychological problems and maintain that more efforts focusing on improving the perceptions of their health condition and social support to improve their psychological well-being should be made. They further commented that in China, policies have been implemented to improve HIV/AIDS prevention, treatment, and care services, although these policies mainly focused on physical health and not on the psychological health of PLWHA.

In a study done in Zambia, it has been established that although PLWHA have increased access to (ART), not all of these patients carry on with treatment as required. Some patients are reported to have stopped taking the treatment (Mwale, 2016). In addition, it was discovered that a number of factors influence these patients to stop taking the treatment and among these are social-related factors, factors in the health care system and economic factors.

South Africa is reported to have more than 6 million people living with HIV, of which 2.4 million have been initiated on Antiretroviral Treatment (ARV) (Nyasulu, 2016). Chipangura (2013) mentions that there is no cure discovered for HIV/AIDS yet, but people living with this disease live longer when using treatment, though they still encounter challenges in their way of life. Hence this study focused on the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape, South Africa.

1.2 PRELIMINARY LITERATURE REVIEW

Studies have been conducted on the psychological well-being of PLWHA and various important factors which are discussed below have been mentioned.

1.2.1 Positive living

Positive living is described as having positive emotions and engaging in the best possible experiences that result from being involved with ones' challenges of HIV/AIDS (Seligman, 2011). Meaningful life reduces psychological and social effects of HIV/AIDS, positive accomplishment is believed to lead to the achievement of goals, and challenges PLWHA are faced with (Seligman, 2011). The Biopsychosocial model of Engel **(**cited in Ritter and Lampkin, 2012) argues that human beings are biological, psychological and social beings who act in certain ways that could either promote or damage their health. Ritter and Lampkin (2012) elaborated that a disturbance in any area of human functioning tends to affect all other areas, therefore a biological disturbance, such as being affected with HIV/AIDS is bound to affect the individual's psychological and social well-being. In addition, psychological influence on HIV/AIDS presents with stigma and discrimination, tend to psychologically affect PLWHA in a negative manner and the social influences include the socio-economic status of PLWHA. Furthermore, those who lack financially, tend to suffer as they cannot have adequate meals to take with the ART, moreover, those who lack social support tend to suffer alone, thus feeling helpless (Ritter & Lampkin, 2012).

1.2.2 Healthy lifestyle

Liu et al. (2014) maintain that a healthy lifestyle includes good physical health, social health, and psychological well-being. Citing from Shostak (2017) on the Healthy Lifestyle Theory on the convergence of agency and structure, the idea that not everybody has been provided with equal opportunities to be healthy is demonstrated. The agency refers to one's ability to choose an action that supports health, especially in PLWHA and the structure refers to the sets of mentally sustaining schemas and resources that empower social action. The structure is further classified into four categories, which are class circumstances; age; gender and race; collectives and living conditions (Cockerham, 2013).

Elaborating from this theory, in lower socio-economic families, unhealthy eating habits are bound to occur due to low income. This affects someone living with HIV/AIDS negatively. The Eastern Cape Province is one of the poorest Provinces in South Africa (Acheampong, 2015), and the Province has many PLWHA of which their lifestyle is affected because of poverty. The most affected age group is in the 15-24 years and more females are affected because of the anatomical structure and socio-economic factors (Yaya et al., 2015). Shisana et al. (2014) stated that the majority of the affected ethnic group are Black South Africans. In addition, they state that collectives entail a group of people linked together according to religion and shared norms and values hence PLWHA tend to gather together to share how they cope with HIV/AIDS and how religion or spirituality helps them. Lastly, because of their living conditions, inability to access basic amenities, personal safety and how they account for disparities to access health services, PLWHA in many instances suffer in rural areas like the former Transkei homeland as they lack development in their areas (Leibbrandt et al., 2010).

1.2.3 Coping

Mukund and Gopalan (2015) note that PLWHA respond differently when discovering about their condition. This comes down to one's abilities and strengths on how one will cope with the disease. Mental well-being and the quality of life may help in better management of stress and can facilitate adaptive coping among PLWHA. In addition, they state that many PLWHA find it challenging to attend to the daily tasks of living and to have enough energy and vitality to engage in an active social life while managing the disease. Drawing from Lazarus and Folkman's cognitive model of stress and coping, there are two major coping strategies, namely: problem-focused and emotion-focused strategies. Problem-focused strategies occur when individuals deal with the cause of the problem of finding solutions about a problem and learn new skills to manage the challenges involved in HIV/AIDS. Emotion-focused strategies involve releasing negative emotions and replacing them with positive emotions (Lazarus & Folkman, 1984).

1.2.4 Support systems

Qypi (2017) believes that the family plays an essential role in supporting PLWHA. In his study, Qypi established that all participants pointed to the fact that they were fully supported by their families and they see their families as their anchor, strength, and hope in the fighting of HIV/AIDS. This encourages PLWHA to divulge their status without being prejudged and stigmatized. This provides psychological well-being and it increases self-acceptance and self-esteem that lead to positive psychology and improved quality of life. Furthermore, PLWHA get encouraged in dealing with HIV/AIDS in a positive manner when they get more support from care providers, families and societies at large, resulting in the improvement of their psychological well-being.

1.3 RESEARCH PROBLEM

WHO (2014) is of an opinion that the psychological well-being of PLWHA is primarily dependent on how they approach life after they have learned about their HIV status. It is noted that PLWHA need to be able to access a broader range of health care services and general care interventions in addition to the comprehensive HIV prevention, treatment and care interventions available (WHO, 2014). Clark, Maupin Jr. and Hayes (2012) stated that on learning about their HIV-positive status, people respond in various ways, as some display disbelief followed by anger, while others display responses such as shock, fear, depression, and helplessness. They further stated that these people worry about health deterioration and death. They emphasized the fact that even with the introduction of ART and the prolonged life of PLWHA, many still experience psychological challenges like stigma and discrimination. Having noticed the efforts on how the government and non-governmental organizations (NGOs) have been actively involved in providing treatment and putting together preventative measures towards HIV/AIDS, the researcher is interested in how these people cope after they have been provided with treatment and whether there has been any follow-up on their well-being since provided with treatment. It is against this background that the psychological well-being of PLWHA is investigated to determine how they cope mentally, physically and socially with the disease.

1.4 RESEARCH QUESTIONS

- What are the factors that influence the psychological well-being of PLWHA in Lusikisiki?
- What are the strategies that PLWHA use to deal with the consequences of stress in Lusikisiki?

1.5 RESEARCH AIM AND OBJECTIVES

1.5.1 AIM

The aim of the study is to investigate the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape.

1.5.2 Objectives

- To explore the factors which influence the psychological well-being of PLWHA in Lusikisiki.
- To describe the strategies PLWHA use to deal with the consequences of stress in Lusikisiki.

1.6 THEORETICAL FRAMEWORK

The study will be backed up by Carol Ryff's model of psychological well-being. This model has an underlying principle that well-being should not be restricted to the biological description as it is a philosophical question about the meaning of a good life. Ryff built her model by looking at a diverse selection of well-being theories and research from other theorists (Ryff & Keyes 1995). Ryff and Keyes maintained that well-being is multi-dimensional and not merely about happiness. They further stated that the model provides a powerful framework through which to analyze and organize one's life and to generate ideas about how to live better which is the case in PLWHA. Ryff identified six categories of psychological well-being. The first category is self-acceptance, which was described as a state whereby one possesses a positive attitude towards him/herself and about the choices he/she had made especially when PLWHA come to terms and accept their status. Secondly, is the personal growth which entails the fact that one sees him/herself growing and expanding. Thirdly, is the purpose of life which is described as when one has goals and direction in life while living with HIV/AIDS and sees life as meaningful. Fourthly, is the positive relations with others, such as warmth and satisfying relations with others. These encourage a sense of belonging in PLWHA. The fifth point is the environmental mastery when PLWHA have a sense of competence in managing their environment. Lastly, is autonomy when one is self-determining and independent in living with HIV/AIDS (Ryff & Keyes, 1995).

1.7 SIGNIFICANCE OF THE STUDY

Rao, Rababuram and Kotian (2016) maintain that HIV infection has a major impact on the mental health of a person, which can lead to cognitive impairment, mood and anxiety disorders. Furthermore, the emotional and physical challenges impair the quality of life of PLWHA as this occurs due to the stigma attached to the disease. In addition, a psychological impairment that is found among PLWHA affects prognosis, adherence to medications and impedes treatment, which is why it is important that these challenges are treated, to improve the health and the quality of life of the affected people. Rao et al. (2016) also mention that PLWHA require total care and psychological support, which is usually in the form of counselling as they need to be integrated with the new information of being tested positive into their existing identity. As PLWHA continue to live longer, there seems to be a gap in the literature on their psychological well-being after accessing and the availability of ART. This study, however, brings new knowledge to existing knowledge which assists in making new policies regarding PLWHA and in their empowerment with the society at large. The study also helped PLWHA to overcome their challenges by attending clinics and wellness programmes available.

1.8 DEFINITION OF TERMS

1.9.1 Psychological well-being:

“Is a general term used to refer to the well-being related to one’s psychological state including subjective, hedonic, eudaimonic and evaluative well-being” (Pluess, 2015).

1.9.2 People Living with HIV/AIDS (PLWHA):

“Refers to infants, children, adolescents and adults infected with HIV/AIDS” (WHO, 2014).

1.9.3 Human Immunodeficiency Virus (HIV):

“Is a virus which weakens the immune system, ultimately leading to AIDS” (UNAIDS 2014).

1.9.4 Acquired Immunodeficiency Syndrome (AIDS):

“Is an epidemiological definition based on signs and symptoms. It is caused by the immunodeficiency virus, which interferes with the body’s ability to fight infections” (Van Dyk, 2008).

1.9.5 Antiretroviral Therapy:

“Refers to the medication that helps to keep opportunistic infections under control” (Rosenthal, 2017).

1.9 CHAPTER OUTLINE

Chapter one presents the introduction and the background of the study. Chapter two reviews the existing literature and theoretical framework. Chapter three is the research methodology applied and this focuses on the study area, the research design, population, sampling, research instruments and procedure of data collection. In chapter four the researcher focuses on data collection, analysis and presentation. In chapter five, the researcher presents the major conclusions on the findings and proposes possible recommendations based on the findings.

CHAPTER 2. LITERATURE REVIEW

2.1 INTRODUCTION

Dawidowicz (2010) commented that it is of paramount importance that the researcher revises any available material on his or her topic of interest in order to be clearly formulated into a research problem. The only way that a researcher would be able to get this information is to search and explore whatever material available in publications, whether from the libraries, books, internet or any other available resources, which is relevant to the topic of the study at hand. Machi and McEvoy (2016) maintained that a literature review is an examination of what other researchers know about the study area of interest and the main aim is to find out how other researchers had presented the knowledge and research-based theory on that particular topic. De Vos et al. (2011) further mentioned that literature reviews contribute to making a clear understanding of the nature of the identified problem and what it means, as well as laying a foundation based on the existing knowledge that is relevant to the study. The following will, therefore be a presentation of the literature review related to the present study.

2.2 LOCATION OF LITERATURE REVIEW

The literature review of the present study is situated in the domain of Social and Health Psychology. This review is organized using research questions and concepts that are evident in the research title and from the objectives, which will also assist the researcher when interpreting the findings of the study. The United Nations Agency for AIDS Report (UNAIDS, 2014) on the AIDS plague, reveals that 34 million people had tested HIV-positive and were living with the disease globally at the end of 2011. Given that, there is an inconsistency in the bearing of HIV/AIDS across the globe, Sub-Saharan Africa, however, continues to be the most relentless affected region in Africa. Amoateng, Kalule-Sabiti and Oladipo (2015) mentioned that HIV/AIDS has affected the continent of Africa, more especially Southern Africa, in the most brutal manner regardless of the global nature of the disease. Countries around the world have reacted and responded positively in adopting new WHO drug guidelines regarding ARV treatment, which led to an increase in the number of people who had to be provided with ART to about 85% of all those who tested HIV-positive and living with the disease (WHO, 2014). In low and middle-income countries, about 11.7 million PLWHA received ART in 2013, which signified that in three people living with HIV/AIDS, one patient received treatment in these countries. The provision of ART expanded in an amazing manner in the Africa Region of WHO, more especially in those regions situated in the Eastern and the Southern part of Africa. The main aim for the provision of ART to PLWHA is to improve the quality of their life, while at the same time reducing the risk of transmitting HIV to other people (WHO, 2014). This has brought hope for PLWHA, that one can live longer even though he/she has been diagnosed with the disease.

In the year 2017, and according to UNAIDS (2018), it was estimated that South Africa had 7.1 million PLWHA and the government had made huge improvements in ensuring that people get tested for HIV in recent years, which is now almost meeting the first target of the 90-90-90 initiative with 86% of people knowing their status. Furthermore, South Africa is reported to have the biggest ART programme in the world and this has expanded more due to the implementation of ‘test and treat’ guidelines. In addition, in sub-Saharan countries, South Africa is the first country to have fully approved Pre-Exposure Prophylaxis (PrEP) that has been made available to those who are at high risk of being infected with HIV. UNAIDS (2018) established that HIV prevalence remains high in the general population but differs between regions. It is also stated that there are huge improvements that have been largely made on extensive progress in eliminating mother-to-child transmission with the implementation of the Prevention of mother-to-child transmission programme (PMTCT). In addition, more than 95% of HIV-positive pregnant women received treatment in 2016, to reduce mother-to-child transmission. Leisegang (2018) asserted that in 2003, HIV/AIDS treatment programme was launched in Lusikisiki by an international non-governmental organization named Medecins sans Frontieres (MSF), also called the Doctors without Borders, in partnership with the Nelson Mandela Foundation and the Eastern Cape Department of Health. Lusikisiki is one of the poorest and most densely populated areas in South Africa, where less than half of the population live in formal housing and up to 80% live below the poverty line (Leisegang, 2018).

Varni, Miller, McCuin, and Solomon (2012) established that HIV infection has appalling effects on the psychological well-being of PLWHA and rates of depression among these people is estimated to be two to five times higher than the rate of depression among people who are HIV-negative. They further stated that to improve the quality of life of PLWHA, there is a need for one to identify with the experiences of living with the disease, which contributes to negative psychological outcomes such as negative perceptions about one’s interpersonal actions, feelings of hopelessness and desolation due to HIV/AIDS. In the agreement, Qadeer and Aftab (2017) mentioned that progress in providing treatment has made it possible for PLWHA to live longer with the disease, though being HIV-positive can lead to several psychological responses and challenges, which include feeling hopeless, helpless, anxious, worthless and depressed. In addition, PLWHA can encounter all these psychological problems while they find it difficult to accept and adjust to their condition.

Sun et al. (2014), similarly asserted that there is no cure for HIV/AIDS, but PLWHA are able to manage the disease by taking ART, which results in them living longer although they still suffer from grave psychological predicaments even with the access to treatment. Sun et al. (2014) are supported by Manhas (2014) who mentioned that there have been tremendous efforts by the government and NGOs in providing services to PLWHA, though there are important aspects that have been ignored which are mental and psychological health. He further emphasized that PLWHA require all the assistance they could acquire to incorporate the situation they find themselves in with the right attitude, which will assist and collaborate with the treatment to enhance their way and quality of life. In addition, this together with social support and resources available might assist in eliminating negative physical and psychological impacts that the disease might bring forth. He further claimed that PLWHA had been participating in various studies conducted and had been used as ‘guinea pigs’ for experiments done to test the effectiveness of antiretroviral drugs and this was done without any regard on how this would affect them psychologically.

Rao et al. (2016) maintained that there are various psychological issues such as stress, anxiety, and depression which manifest among PLWHA and someone with depression may have a number of symptoms such as feeling of worthlessness, sadness, helplessness, feelings of guilt, lack of interest in performing any activity, suicidal thoughts and changes in eating and sleeping habits. In addition, they asserted that PLWHA may experience all these symptoms because they realize that the condition is not curable and the situation in which they find themselves in, will clearly result in them being depressed. Furthermore, stigma societal attitudes, negative attitude of patient care provider and reduction of care from family members are other environmental barriers that cause stress on PLWHA which leads to hopelessness. Rao et al. (2016) asserted that all these factors decrease the productivity of infected persons thus reducing their quality of life. They also commented that along with the fact that PLWHA are facing emotional problems, this will also lead to a few physiological symptoms, such as digestive problems, increased blood pressure, changes in the immune system and changes in hormonal functions which will worsen the severity of mental problems. They asserted that social support, especially support from the family members plays an essential role to reduce progression of the disease thus enhancing the way of life of PLWHA.

2.3 WELL-BEING

Well-being refers to “the full range of aspects that contribute to an individual assessment of his/her quality of life, including social aspects, physical and mental health as well as feelings of happiness and safety” (Deci & Ryan, 2008). They further indicated that well-being is defined using two perspectives, which are the hedonistic and the eudaimonic perspectives. A hedonistic view on well-being focuses on subjective experiences, feelings towards life, that is, emotional well-being such as feelings of happiness, as well as positive and negative affect. In this view, well-being can be accomplished by pursuing pleasure and enjoyment whether physical, cognitive or emotional. It refers to positive effect that is related to having material objects and action opportunities one wishes to possess. It defines well-being as a cognitive evaluation of life, with a positive outlook and without any negative emotions (Deci & Ryan, 2008).

Huta and Waterman (2014) mentioned that in eudaimonic perspective, well-being focuses on functioning in life and it is not determined by being happy, but can be achieved when one meets his or her goals in life, a stage referred to as self-actualization. They further argued that for well-being to be defined, there are four essential elements that need to be present which are authenticity, meaning, excellence, and growth. They referred to authenticity as when one’s true self is in line with his/her values as he/she stays connected to those values in his/her actions and in the way he/she interacts with those around him/her and the environment. Meaning is referred to as when one understands a bigger picture, which provides one’s sense of identity, purpose and how one is connected to others, society and the ecosystem. Excellence is referred to as striving for higher quality and higher standards in one’s behaviour, performance, accomplishments and ethics. Lastly, growth refers to pursuing and meeting one’s personal goals, as well as learning and looking at presenting challenges so that one matures as a human being (Huta & Waterman, 2014). In this perspective, well-being is when one realizes his/her true nature. It is not seen as how much happiness one has or what he/she has done in life for him/her to be happy, but rather a subjective experience, which is a result of doing what is right and expected of him/her. It refers to that feeling one has made all the effort in trying to meet his/her goals in life, which would assist him/her to go forward in life (Joseph, 2015).

Mukolo and Wallston (2012) on the other hand, emphasized that psychological well-being is made up of two dimensions, which are independent, known as the positive and negative affect. They asserted that in some instances the negative mood is associated with immune-suppression that leads to disease progression though, in some, this was not the case as psychological distress had a strong positive association with greater HIV disease progression. It was further acknowledged that PLWHA who had accessed coping with resources that could assist them psychologically, live healthily and positively with HIV, thus enhancing their well-being. In addition, they mentioned that even though the outcomes on how psychological negative and positive effects impact one's physical health are thoroughly communicated, not much have be clearly reported in the HIV literature on how these affect one's psychological well-being. Furthermore, the reason for this would be the fact that most studies on psychological well-being focus more on the negative feelings and they do not take into consideration the positive feelings.

Mukolo and Wallston (2012) further argued that in the available literature, much has not been done concerning the positive psychological aspects of PLWHA, as this literature is far lesser than the literature on negative factors and they mentioned that their aim was to contribute in growing literature, which investigates positive factors that might contribute to psychological well-being among PLWHA. They also commented that in PLWHA, psychological well-being could be improved and maintained by applying three resources for coping, which are a sense of consistency, looking at life in a positive and hopeful manner and believing in oneself that he/she has the ability to make it in life. Mukolo and Wallston (2012) also established that, people who are consistent are more likely to have the ability to look at distressful situations as less stressful and cope more effectively with whatever challenges that may come with those situations, unlike those who are inconsistent. In addition, they mentioned that although these three are desirable among PLWHA, the most practical attribute among these is the ability of being able to make things happen for one's self in life, which involves having confidence in oneself than the two other positive attributes.

2.4 FACTORS AFFECTING FLOURISHING AND LANGUISHING OF PLWHA

Keyes et al. (2008) asserted that, eudemonia approach of well-being suggests a continuous assessment of the presence of mental health, which is described as flourishing whereby one experiences positive emotions, positive psychological functioning and positive social functioning most of the time. Furthermore, when living within an optimum range of human functioning and the absence of mental health as languishing, likewise when one lives a life that feels hollow and empty. In addition, flourishing includes components such as cultivating strengths, subjective well-being, goodness, generativity, growth, and resilience. In addition, moderate mental health describes a condition where people are either flourishing or languishing. Mukund and Gopalan (2015) established that HIV leads to a general decline in how one lives his/her life and that PLWHA in mental health are faced with numerous psychological and biological problems, which make them different from other people. The various factors will be discussed below which might cause languishing or flourishing of PLWHA.

2.4.1 Disclosure of one’s HIV status.

Dankoli et al. (2015) referred to disclosing one’s HIV status as revealing to other people that one is living with HIV/AIDS. They mentioned that disclosing one’s HIV status is a difficult and yet an important decision for all infected people as it might have positive effects on individuals’ health, such as increased social support and decreased stress. Naigino et al. (2017) claimed that disclosing one’s HIV status is linked with a person living with HIV/AIDS and being supported by his/her spouse, especially the pregnant women living with HIV/AIDS. Dima, Stutterheim, Lyimo, and De Bruin (2014) further asserted that disclosing one’s HIV-positive status might have an impact on the psychological well-being of PLWHA as much as on their behaviours in the prevention of HIV transmission, such as testing for HIV, negotiating safe sex and many others, thus leading to flourishing of PLWHA.

Naigino et al. (2017) also maintained that from the public health perspective, HIV disclosure had contributed immensely to HIV transmission reduction, primarily through condom use and motivation of sexual partners for HIV counselling and testing. Furthermore, disclosing HIV status to a sexual partner creates room for the couple to make informed choices about their sexual behaviour, by allowing them to engage in preventative and risk reduction behaviours thus enhancing the quality of life. In addition, knowing one’s HIV status helps the individual’s family and friends to take precautions to prevent transmission during their daily interactions with them, increasing opportunities of obtaining social support as well as easy access to necessary support and treatment for coping with the disease. In addition, in most cases for PLWHA, disclosure is stressful as there is a fear of negative reactions, such as barriers like stigma, rejection, discrimination, violence and abandonment rather than relief which remains a challenge for them thus leading to languish.

Chipangura (2013) mentioned that HIV/AIDS brings out the worst when individuals have to face challenges, such as stigma and discrimination by their loved ones, families and their communities after disclosing their HIV status. Naigino et al. (2017) further mentioned that despite the efforts made in order for the improvement in the access of antiretroviral regimens, disclosing HIV status stays at the centre to improve maternal and child health outcomes. They further established that women who were pregnant and who did not disclose their HIV status had the lowest levels of Prevention of mother-to-child transmission (PMTCT) service utilization that put the lives of unborn babies at high risk of being infected with the disease. This could lead to languishing of PLWHA as they would be aware of the kind of danger they put their babies into, which was why women living with HIV/AIDS were always encouraged to reveal their HIV status so that they could increase social support in order for them to give birth to healthy babies.

2.4.2 Stigma and discrimination.

Yaya et al. (2015) established that in many countries, stigma and discrimination continue to hinder effective prevention, communication and other program intervention responses to HIV/AIDS. They referred to HIV related stigma as the unfavourable attitudes, beliefs, and policies directed towards PLWHA, as well as the severe shame associated with HIV/AIDS by their loved ones, individual, family or community. Lyimo et al. (2014) added that it is a process of devaluation that leads to shame and extensively disgraces another human being. Dahlui et al. (2015) commented that stigma and discrimination are the major challenges hindering the efforts and the achievement of controlling HIV/AIDS from spreading as these detach PLWHA from the society and have negative force on their value of life. They further pointed that stigma is discussed in various forms. There is perceived or public stigma, which includes evasion, elimination, negative response, segregation, violent behaviour, physical distance, and awkwardness when interacting with people and blaming. Furthermore, there is also what is known as internalized stigma, which occurs when a PLWHA believes what other people say in public about him/her thus resulting in low self-esteem and anger. These features have damaging consequences for the health of PLWHA whether socially, mentally, emotionally and physically.

Dahlui et al. (2015) mentioned that some PLWHA use good coping skills that lead to disclosure, which may have beneficial consequences for PLWHA, such as greater psychological well-being, more closeness in relationships, more social support, improved treatment adherence and safer sex, which can also safeguard the psychological well-being of an individual from the harsh and harmful results of stigma and discrimination, thus leading to flourishing. They maintained that when the levels of stigma are high, they prevent PLWHA from disclosing their status, which could be detrimental to their health, thus leading to languishing. Tsai et al. (2013) further mentioned that the problem of stigmatization and discrimination among PLWHA is predominantly more extensive in sub-Saharan Africa because of weak health systems, jointly with the pitiable lawful and principled structures.

2.4.3 Body image.

Alexias, Savvakis, and Stratopoulou (2016) asserted that lipodystrophy is the unusual loss of subcutaneous fat, which is noticeable on the face of a person living with HIV/AIDS. Plankey et al. (2013) on the other hand described lipodystrophy as the loss or gain or both of body fat that is associated with metabolic abnormalities. Alexias et al. (2016) further mentioned that the changes displayed in one’s body and the stigma that is often the result of self-blame by PLWHA, together with other effects of illness, such as the changes one has made for his/her life and the relationships one has established, which need to be changed and be in line with the present situation after diagnosis, could have a negative effect on one’s state of mental health. They asserted that these sudden changes may bring confusion and be a barrier for one’s goals or life, more especially with a chronic illness such as HIV/AIDS. Furthermore, the way one’s body is being shaped and presented is vital for one’s identity to those around him/her in the case of PLWHA. In addition, the changes of the body that can be seen by other people, which are the result of lipodystrophy are a source of mental discomfort for PLWHA, when they realize that they no longer have control over their bodies, which therefore brings dissatisfaction, and these changes are the result of the virus and the side effects caused by the medication. They also maintained that the reflection of PLWHA had been mainly connected with this condition called lipodystrophy, however, individuals who have displayed the changes caused by it tend to lose confidence in themselves and feel awful and depressed about their physical form thus, leading to languishing.

Plankey et al. (2013) commented that the fact that people see changes in the reflection of PLWHA, can determine how they would display stigmatization which will, in turn, make the experience of PLWHA either to deteriorate or improve. They further maintained that with those symptoms which are more noticeable, PLWHA are identified and blame with rejection, thereby are more open to feeling guilty and shameful. In general, it was demonstrated that PLWHA have a negative image about themselves as they have evident changes in their bodies, which are often extreme in some cases as a result of HIV and the side effects caused by the medication. In addition, PLWHA reported that they felt as if their bodies had been alienated, thus resulting in one feeling as if his/her identity had been transformed, thus resulting in languishing of PLWHA. They also asserted that visible symptoms of HIV/AIDS do not cause distress only to PLWHA who have been trying to hide their status but also to those who have come to terms with their HIV status and are ready to face HIV.

Alexias et al. (2016) established that the majority of PLWHA, that participated in the study conducted, recognized a positive meaning to the disease, as they emphasized that there are positive changes that HIV had brought into their lives. They further mentioned that in many ways PLWHA considered living with the disease as a means that motivated them to meet certain goals in their lives, which they never thought possible, thus giving them a positive change of direction in life. They asserted that it is, therefore, significant to note that some PLWHA have looked at the disease in different ways and have come up with positives, thus leading to flourishing.

2.4.4 Positive living.

Liamputtong (2013) mentioned that living positively plays a vital role in the life of PLWHA as it allows them to fight against the negative images of the disease, thus dealing with their condition and environment in a positive way. Furthermore, people react in many ways upon learning about their HIV status, but they gradually improve and gain the courage to come to terms with their status when they realize that they have support and assistance from their families, health and home care providers, counsellors and the community at large. It is at this stage that PLWHA are considered to have begun living positively with HIV/AIDS, thus leading to flourishing. Poudel, Buchanan, and Poudel-Tandukar (2015) commented that PLWHA who practice unsafe sex might affect their health in a negative manner as well as increasing the jeopardy of contracting other sexually transmitted diseases, which could exaggerate HIV disease progression leading to languishing. Furthermore, unsafe sex could increase the risk of re-infection, while contracting multiple HIV subtypes, which could complicate ART and increase the viral load, while contributing to the spread of the virus highlighting issues of languishing. In addition, since it is evident that many PLWHA intentionally continue to engage in unsafe sexual practices even after finding out that they are HIV-positive, there is a pressing need to develop ways of intervening in modifying their behaviours and perceptions in order to foster and enhance safer sex practices among them.

However, Poudel et al. (2015) asserted that their study demonstrated significant protective effects of a theory-based educational intervention to strengthen a range of factors known to be associated with preventive behaviours. They maintained that these factors include HIV transmission knowledge, extrinsic reward, intrinsic reward, perceived severity, vulnerability, self-efficacy, response-efficacy, response cost, and condom use intention with different serostatus partners among PLWHA. Furthermore, the contents of the intervention were premeditated to be culturally fitting with regards to the population that was studied. For example, PLWHA in the study area had little knowledge about the possible consequences of having unprotected sex, especially in as much as seroconcordant relationships are concerned and interested in learning more about the topic. Poudel et al. (2015) also argued that educational interventions are needed to be provided to those who participated in the study, with a chance to discuss such issues, while improving their beliefs regarding HIV, condom use and behaviours, thus leading to flourishing.

2.4.5 Healthy lifestyle.

Rao et al. (2016) asserted that apart from the health issues faced by PLWHA, they also need to live a healthy lifestyle, which includes good physical health, social health, and psychological well-being. They commented that it is the responsibility of the family to motivate PLWHA to exercise control, alter their sexual behaviour and to have a nutritional diet in order to maintain their health. WHO (2014) established that women who are living with HIV/AIDS were reported to be at higher risk of being diagnosed with pre-cancer and invasive cervical cancer, which is a primary cause of death among women in Sub-Saharan Africa, Latin America, and Asia. This type of cancer is avoidable and curable if diagnosed and treated in its early stages (WHO, 2014). It is everyone's responsibility more especially PLWHA, to have a healthy lifestyle in order to live longer. That is why women living with HIV should make it their main concern that they are screened for cervical cancer in spite of age, CD4 count and viral load, as part of their lifestyle leading to flourishing (WHO, 2014). On the other hand, women who do not seek screening for cervical cancer from their health care centers/clinics tend to present with cervical cancer in its last stages, thus exposing them to languishing and death (Borruto & De Ridder, 2012).

2.4.6 Coping.

Folkman (2011) asserted that over a period, health psychology researchers have drawn upon 'stress and coping theory' research to develop interventions. These are aimed at enhancing the capacity of individuals, to manage the ongoing challenges of HIV/AIDS, which results in using certain coping strategies by PLWHA for dealing with the demand of the disease, thus fostering better physical health outcomes. She further commented that coping strategies involve direct action, such as active coping, planning and positive appraisal, which includes acceptance and positive reframing that are constantly connected with enhanced psychological and physical health and well-being, thus leading to flourishing. On the other hand, coping that involves disengagement includes behavioural disengagement, denial and substance abuse that is related to poorer mental and physical outcomes leading to languishing.

Folkman (2011) stated that reducing stressful events require one to come up with coping strategies in order for him/her to deal with those events, which include problem-focused coping, whereby a person needs to take direct actions in order to reduce the effects of a stressful event by shifting the circumstances that produce the problem. In addition, people can also use emotion-focused coping when facing stressful situations, much of which is exactly directed at alleviating misery by temporarily shifting one's thoughts and focusing those thoughts and the behaviours on something positive. These strategies occur when a person changes the way he/she thinks mostly by altering his/her goals and values, for example, one may see the humour in a difficult situation. These strategies are therefore directed at challenging personal assumptions. This can be done by practising various relaxation techniques, such as meditation and other systematic relaxation procedures. These strategies may lead to flourishing, while those who do not practice them might experience languishing.

Bhat et al. (2015) asserted that forgiveness, which includes forgiving oneself and others, is a result of accepting one's status and had been considered as an efficient approach of coping with PLWHA resulting to flourishing. Furthermore, expressing forgiveness motivate PLWHA to protect others from infection through protected sexual intercourse. In addition, psychological strength is also measured as an important factor for coping with stressful situations, as greater psychological strength and inventiveness are connected with increased social support and decreased depression. On the other hand, Kremer and Ironson (2014) in a longitudinal study conducted found that spirituality has been used as a coping strategy by PLWHA. They mentioned that a positive view of God and being more involved in spirituality after diagnosis lowers the progression of the disease, thus leading to flourishing, whereas viewing God in a negative way accelerates disease evolution resulting in languishing. Furthermore, they described spirituality as a broad concept, which may include cognitive, emotional and behavioural aspects together with spiritual activities. They conceptualized spiritual coping as a centre of attention on the connection one has with the higher presence that helps with meaning-making, positive reframing, self-empowerment as well as growth on a personal and spiritual level. However, spiritual coping could be detrimental in some instances, where a person living with HIV/AIDS refuses to take treatment as he/she determinedly believes that God would restore him/her to health from the disease leading to languishing. They concluded that this coping strategy has either a negative or a positive effect depending on the circumstances.

In addition, Hussen et al. (2014) included resilience as a form of coping and they mentioned that it is defined as a positive alteration in the perspective of hardship that seeks to identify with processes in the society to foster healthy coping, thus leading to flourishing in PLWHA. They further mentioned that in addition to the physical harm due to HIV infection, PLWHA in developing nations face various challenges in general, concerning their health and welfare, which include scarcity of resources, restricted healthcare services, and stigma, and the discrimination by people within society which leads to languishing. In addition, these socio-economic and cultural factors frequently become obstacles to HIV care, while intensifying pressure on systems put into place to assist in supporting PLWHA which ends as a negative outcome on mental and physical health. Furthermore, many PLWHA preserve adherence to treatment in a more successful manner, by being involved in HIV care consistently, while carrying on with living their life in a positive manner, thus leading to flourishing using resilience.

2.4.7 Support systems.

Casale (2014) stated that social support is the availability of people whom the individual trusts, whom one can rely on and who can make an individual feel loved and cared for. In the case of PLWHA, this could be applied by the provision of psychological and material resources by people within one's social network. He further stated that social support in PLWHA is linked with health powerful benefits, more especially to those who are vulnerable to stigma and have less access to social resources. When a PLWHA has social support from families and friends, he/she can be able to bear whatever challenges he/she comes across when living with the disease, because he/she is assured that there are people who care. Casale (2014) mentioned that social support is important in calming the effect of stressful events and reducing the incidence of disease in PLWHA. In addition, support systems enable PLWHA to cope better with the disease, leading to a sense of fulfilment, satisfaction, and hope. He mentioned that it can also encourage open disclosure about the disease status and a reduction in stigmatizing and discriminatory attitudes.

Gaysynsky, Romansky-Poulin, and Arpadi (2015) established that PLWHA whohave support from people around them are more prone to adjust well with HIV/AIDS as they have people who are always there to share their burdens with, thus reducing stress linked with HIV and leads to better psychological outcomes among them. They stated that when PLWHA do not have support, they have constant worry, stress, and anxieties about the future, which can have a negative impact on poor health outcomes and PLHWA can also have a negative influence on the implementation of health-enhancing behaviours. Gaysynsky et al. (2015) identified support groups as one important mode in assisting people who are facing grave ailments, such as HIV/AIDS and substance abuse issues. This shows that meeting other people facing related challenges helps others who are going through the same route to feel less secluded as taking part in these support groups fosters hope and a feeling that one belongs, which can bring into being, positive results, such as the improved condition of life and a prolonged life, thus leading to flourishing. Gaysynsky et al. (2015) further mentioned that since the advancement of computer-mediated communication, societies suffering from various illnesses had depended entirely on the internet.

Likewise in their observation, Liu et al. (2013) established that research has the constructive outcome of shared support in reducing psychological distress on PLWHA. They further mentioned two types of social support, namely structural and functional support. The structural social support is described as the social network, which consists of people who have resources in assisting those in need, while functional social support brings about procedures or specific functions that might be passed on by individuals in a community in the form of psychological and substantial that are in the form of knowledge and companionship support. However, functional support appears to be the one that is more relevant to PLWHA. In addition, social support is the most vital factor in reducing stressful situations, especially in PLWHA when trying to cope with the situation they find themselves in. Furthermore, social support had been split into emotional, appraisal, informational and instrumental support which are all provided by family, friends, relatives and the significant others, thus leading to flourishing.

Heylen, Panicker, Chandy, Steward, and Ekstrand (2015) also mentioned that another aspect in support system is food insecurity, which is a plight of many PLWHA and due to this, mental ill health like depression, anxiety and behavioural pathways, such as risky sexual behaviour and poor adherence may hasten disease progression. Tarasuk, Li, Mitchell, and Dachner (2018) refer to food insecurity as inadequate access to sufficient food due to financial constraints. It is therefore of vital importance that when looking at the support systems, strategies to assist PLWHA be able to provide sufficient food for them should be taken into consideration and these would come from the government or any other support system. In addition, the value of life and life contentment had been found to be spoilt by food insecurity, because when PLWHA worry about what to eat in order for treatment to be effective, it becomes a challenge that affects their health, thus leading to languishing. Furthermore, food insecurity and ill health are interrelated in the studies conducted on both PLWHA and those living without the disease. Tarasuk et al. (2018) also mentioned that improved nutrition may not only make better HIV physical outcomes, but unlimited food security might also alleviate the psychological anguish and increase the value of the life of PLWHA.

Oetzel et al. (2014) noted that perceived support, which is explained as the surety that resources are available to an individual when required is strongly connected to the well-being and the mental health than the actual support. Oetzel et al. (2014) included two categories of social support in reference to friends and family, which are emotional and instrumental. They asserted that emotional support includes being provided with love, confirmation and caring, while instrumental support contains substantial assistance. Furthermore, they considered two types of social support from health care providers, which are informational and emotional support. In addition, they included the perceived quality of information from service providers as sources of information, given the complications of the way treatment is taken, among other aspects for PLWHA. They added that health care providers offer caring and affirmation, which is emotional support that is predominantly essential when talking about social stigma for PLWHA resulting in flourishing. On the other hand, when PLWHA do not get all these types of support they may languish and die.

2.5 RYFF'S MODELS OF PSYCHOLOGICAL WELL-BEING

Henriques (2011) asserted that many years ago a model of psychological well-being was brought forward by Ryff (Ryff, 1989) to tackle the issues that were left out in the formulations of 'positive human functioning' which existed in the 1980s. He further mentioned that Carol Ryff was motivated by an idea that well-being should not be restrained only to the medical description, but be also looked at as a 'philosophical' inquiry about the purpose of a decent life. He commented that Ryff was also motivated by the fact that the psychological theories of well-being at that time, were short of experimental firmness, as they were not reliable and could not be trusted. Ryff (1989) drew her motivation to create a theory that joins philosophical questions with scientific empiricism from a diverse selection of well-being theories and research from theorists, such as Abraham Maslow and Carl Jung, as well as from Aristotle to John Stuart Mill. She referred to well-being as multi-dimensional and not merely about happiness or positive emotions. Henn, Hill, and Jorgensen (2016) mentioned that Ryff investigated psychological well-being in relation to development and growth and she developed a model consisting of six dimensions of psychological well-being that are discussed as follows and shown in figure 1 below:

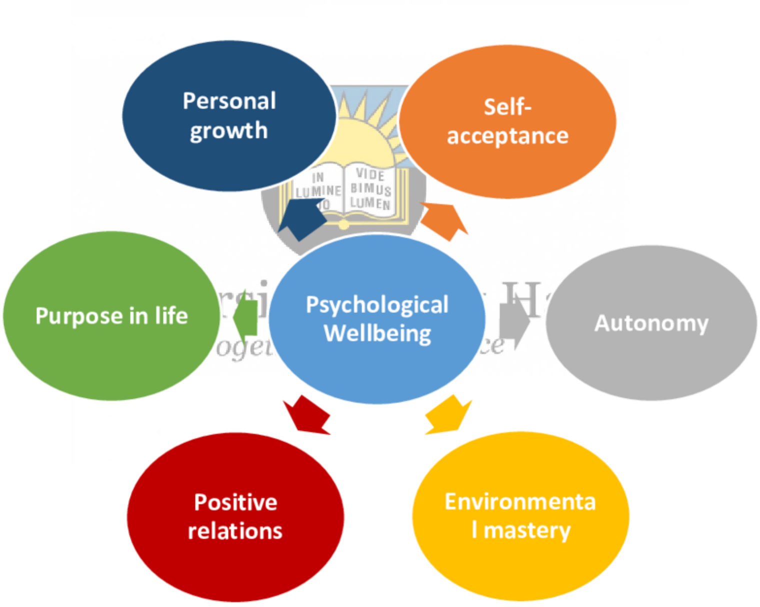


Figure 1.Diagram of six dimensions of psychological well-being (Ryff & Keyes, 1995).

2.5.1 Self-acceptance.

Ryff and Keyes (1995) described self-acceptance as a state whereby one possesses a positive attitude towards oneself by accepting him/herself and how one feels positive about the choices he/she had made, while Henn et al. (2016) maintained that self-acceptance is to have a reasonable insight of self, which includes good and bad qualities and still be able to accept one's self regardless. These characteristics are evident to PLWHA when they come to terms and accept their status. Those who experience low self-acceptance tend to feel dissatisfied and disappointed with themselves. This might be due to denial in PLWHA. Levi-Minzi and Surratt (2014) asserted that stigma related to HIV has a major effect on the health and well-being of PLWHA and this usually results in the taking of alcohol and substance abuse to ease the pain of living with the disease. Levi-Minzi and Surratt (2014) found that factors that influence behaviour may include ARV adherence and diversion that is also extensively related to internalized stigma. Furthermore, PLWHA who adhere to ARV treatment appeared to be less affected by stigma, revealing their HIV status and building relationships in general. In addition, PLWHA who have been living with HIV for long periods experience less stigma and discrimination as they have accepted themselves and disclosed their status, while those who have been recently diagnosed experience higher levels of stigma and discrimination linked to HIV/AIDS. They established that PLWHA that have been diagnosed for long periods tend to experience less stigma, which is connected to the disclosure and accepting one's self. On the contrary, those who have been recently diagnosed experienced higher levels of stigma linked to HIV/AIDS (Levi-Minzi & Surratt, 2014).

Teti, French, Bonney and Lightfoot (2015) commented that women living with HIV transformed their lives in a positive manner as they experienced being healthy, stronger in spirituality, self-accepting and feeling confident to improve their quality of life while growing and recovering. In addition, women reported having persisted, persevered and created positive changes in life, regardless of barriers that might be on their way. This is the result of self-acceptance whereby one accepts who she has become regardless of how bad the circumstances may seem. Furthermore, self-acceptance entailed accepting living with HIV, handling the stigma through acquiring skills that assist one in life, focusing on spirituality and surviving stigma. Rohleder, McDermott and Cook (2017) mentioned that some men disclose their HIV-positive status to their family members and accept their HIV status even though they put great emphasis on the impact that HIV has on their sense of self. Furthermore, despite self-acceptance, men living with HIV/AIDS complained about the changes caused by treatment with the side effects, which affect their sexual libido that is, there is a sense of loss around their sexual life with a real struggle to reclaim their sexual identity.

2.5.2 Personal growth.

Henn et al. (2016) asserted that personal growth entails growing and the constant developing of a person, striving towards reaching one's goals in life. Strong personal growth occurs when one is having a feeling of continuous development as he/she experiences growth and is open to new experiences. Russell et al. (2016) commented that complete achievement of antiretroviral therapy programmes depends entirely on PLWHA's motivation and ability to manage the condition individually, which includes adherence to medication on a daily basis. In addition, the self-management of HIV status sustains the well-being of PLWHA as it motivates them to continue to live positively. Furthermore, some PLWHA struggle financially, but they tend to recover health-wise because of hope and treatment that enhances their well-being.

Russell et al. (2016) commented that PLWHA accessed available resources through having good relationships with health workers. They get advice and counselling that help to look at their situation more positive, thus seeing the hope for the future and motivating them. Russell et al. (2016) also reported that PLWHA also developed a new network of support through contacts they had developed with others living with HIV/AIDS in the clinics or health centres. Furthermore, PLWHA acquire knowledge and skills to manage their health in the form of a useful framework to manage their condition and to live their life to the fullest. In addition, PLWHA were psychologically adjusting to their condition as they see HIV as a normal disease they coped well with alongside the stigma with regaining self-esteem and finding meaning to life. On the other hand, weak personal growth occurs when one lacks a sense of improvement and one is not open to develop new attitudes (Ryff & Keyes, 1995). In addition, PLWHA's personal growth might be determined by one's interest or lack to come up with new ideas to expand one's territory in life. PLWHA who have high personal growth may strive to develop in another, in spite of living with a chronic disease. These people tend to flourish while those who lack personal growth may remain stagnant in their lives, even if there are opportunities for one to grow.

2.5.3 Purpose in life.

Ryff and Keyes (1995) defined purpose in life as having a clear sense of direction, goals and meaning in life, while Wong (2013) commented that purpose in life is a valuable indicator of positive functioning and feeling that life matters, identifying a sense of purpose and achieving an understanding of one's self and one's life. Wong (2013) further claimed that these aspects are central to one’s meaning of life as they directly affect the well-being. In addition, Wong (2013) mentioned that Plato observed humans and realized that, they are beings who are in search of meaning or purpose, and they automatically get this purpose from their experiences, which include the experiences of life itself. In addition, purpose in life provides one with the sense that life matters and that it is more than what one can imagine. Moreover, when one looks at one’s experience in this way, it builds the cognition that constitutes purpose and understanding. Also, the purpose in life brings together people’s ideas about who they are, the world they live in and how they interact with and react to the people and environments around them, which sustains people through challenging and difficult circumstances. Lastly, purpose in life serves as a buffer against negative traumatic events, which provides a buffering effect (Wong, 2013).

Wong (2013) further emphasized that individuals who report higher purpose in life, appear to report more perspectives that are desirable and outlooks as they have positive perceptions of the world and towards life in general with one’s present and future life. Furthermore, these people report greater future orientation, including greater hope and optimism. However, PLWHA may choose either to take the bull by its horn and see life as meaningful or throw in the towel and look at life as meaningless. In addition, those with a higher purpose in life are likely to be better inclined and equipped to manage life’s challenges as they develop a deeper meaning and understanding of one’s life through suffering.

In support of Wong, Pan (2017) asserted that the purpose in life is important to mental and physical health. Nevertheless, some research has demonstrated the links between many aspects of the purpose of life and various facets of physical health and psychological well-being. Furthermore, purpose in life might however be important to psychological and physical well-being in times of high stress. In addition, through its influences on individuals' management of stressful situations, purpose in life has an effective impact on the health and emotional well-being of a person. Pan (2017) further emphasized that the purpose in life plays a major role in informing individuals when facing stressful situations on the implication of those situations and on how to respond to them. This is reinforced by Folkman (2011) that in encountering stressful situations in life, people respond by using a variety of aspects, such as personal relevance, controllability and likely implications to respond, as determined by how the situation presents itself at that specific time, but are also greatly informed by the individuals' purpose in life. In addition, encountering stress in life may prevent one from developing goals for him/herself with the result that some may leave their work and stay at home with no income, suggesting lack of purpose in life and others might start afresh to develop themselves and fulfill the higher goals they have set for themselves and developing their lives as well.

Wagner et al. (2017) maintained that the restoring of health and getting back to work and other routines of PLWHA, contribute greatly to feelings of normality in life as work is viewed as important for material well-being and feeling of independence more particularly, for the men's fulfillment of their expected role of being providers. Furthermore, work was also reported to be a very important aspect of psychological well-being, as it had a restorative role of helping PLWHA to feel that they had restored what they had lost and regaining their lives after the earlier losses caused by HIV. In addition, the work is considered to have a therapeutic value while helping PLWHA to stay busy, thus reducing negative thoughts**.**

2.5.4 Positive relations with others.

Ryff and Keyes (1995) described strong relations with others as building a warm, satisfying and trusting relationship with others. On the other hand, isolation and frustration are seen as weak relations with others. One’s sense of belonging depends on how one treats others and in the case of PLWHA, the way one accepts his/her status determines how he/she will interact with those around him/her. Russell et al. (2016) mentioned that positive relations with health workers, especially in the first three months after the diagnosis and the starting of treatment were reported to be very critical for PLWHA as that was a crucial stage in their life. In addition, PLWHA saw the acquiring of knowledge about HIV and ART from health workers as a great psychological resource and emotional boost as it reduces uncertainty and anxiety and provides hope while giving inner strength to carry on. Furthermore, PLWHA find encouragement from a new network of friends from the clinic, not just staff but also others, who shared their experiences while encouraging each other, thus playing an important role in their psychological well-being. Likewise, those who shared experiences felt encouraged in self-management and this enhancing their well-being as it helps to create a sense of belonging to a ‘therapeutic community’ and relatedness solidarity. This means that those who are able to form positive relations with health care workers and other clients tend to learn and gain self-management skills from others and in the process maintain themselves in a healthy manner, thus enhancing their well-being. PLWHA who experience stigma and discrimination, tend to isolate themselves and become depressed, which results in mental illness and languishing.

Rohleder et al. (2017) maintained that good social relationships and a sense of connection are important resources for the well-being of PLWHA, which could enhance psychological coping in times of stress. Vijayakumar and Vijayabanu (2014), in the agreement with Russell et al. (2016) posited that a positive attitude and hope may assist PLWHA to approach their lives in a positive manner despite being ill. They noted that PLWHA were continually bothered by poor care and inadequate services, however, the healthcare sector had generally been pointed to be responsible for AIDS-related discrimination, stigma, and denial. In addition, negative attitudes from staff in health care centres generate anxiety and fear among many PLWHA. Furthermore, individuals who take care of PLWHA should also possess that special quality that includes hope not only for PLWHA but also have an ability to transfer hope to their clients and thus enhancing their quality of life. In addition, they reasoned that a positive attitude could have an impact on every aspect of one's life, therefore, PLWHA must maintain a positive approach in living with HIV/AIDS and that the challenges they face would enable to move forward. PLWHA who lack positive relations with others, especially health workers may experience negative attitudes and resort into using far away health centres, where they might not be known because they fear being mistreated and sometimes default on their treatment due to lack of money to travel to these clinics. On the other hand, PLWHA who have positive relations with others may experience positive attitudes and therefore relate positively with people they interact with especially the heath workers, which allow them to freely ask questions that are bothering them for the benefit of their health.

2.5.5 Environmental mastery.

Ryff and Keyes (1995) defined environmental mastery as the capacity to effectively manage one's life and the surrounding world, which is the ability to manage the environment, to mold environments or to choose environments, which align with one's needs and values. Henn et al. (2016) and Fave (2017) described it as one's ability to manipulate, control and effectively use resources and opportunities creating environments that are suitable to one's psychic condition. Fave (2017) identified environmental mastery as a state of mind rather than a behaviour that serves as a remedy to feelings of helplessness. Furthermore, it has gained increased attention in health as it is seen as an important psychological resource where humans, especially men, are the masters of the universe as they are called forth to direct and shape the entire natural realm. Also, environmental mastery is perceived as the ability to manipulate, modify and use the environment, according to the needs and wants of humans because it is made to serve them. This implies that PLWHA are able to employ the available resources, learn from the health workers and maintain their environment to take control of their lives in handling chronic conditions like HIV, inclined to take their treatment regularly, protect themselves from re-infection, maintain a healthy lifestyle and in the process experience a positive quality life.

Ryff and Keyes (1995) maintained that high environmental mastery is when one has a sense of competence in managing the environment, while low environmental mastery is when one has difficulty managing everyday affairs. PLWHA might be able or unable to take control of their lives and the environment, depending on one's state of mind. Acevedo (2012) emphasized that environmental mastery is one's belief and confidence that he/she has the ability to negotiate his/her environmental surroundings. He argued that environmental mastery has two implications for exercise. Acevedo (2012) further stated that the first exercise allows the person to gain a sense of control or mastery of his/her own body, given the invasion of the body by HIV. In addition, this phenomenon had been documented throughout the literature in normal populations, especially within clinical populations, such as individuals living with HIV/AIDS as they perceive their bodies as declining in physical functioning. Furthermore, participation in exercise allows them to gain a sense of mastery and control over their bodies and to develop a positive physical self-perception. The second exercise involves the development of environmental mastery in special populations, such as those suffering from any type of mild to severe mental illness. In addition, exercise interventions had to be specifically developed for people who are in remission from mental illness to help them integrate back to the society and help them gain confidence and environmental mastery over their lives. For example, PLWHA who have a low sense of control of their environment may be able to encounter a lack of mastery by getting into these intervention exercises to fight mental illness, but those who are able to do so may find it harder to change their behaviours and become helpless.

2.5.6 Autonomy.

Akrivopoulou (2015) asserted that autonomy is the ability to make one's own decisions without relying on or waiting for the approval of others and the ability to measure oneself according to one’s own belief and not by the beliefs of others. High autonomy is described as when an individual is self-determining and independent, while low autonomy is when an individual is concerned about the expectations and evaluations of others (Ryff & Keyes, 1995). Autonomy in PLWHA might be affected by how one thinks of him/herself and others. This entails accepting one’s self regardless of how others judge him/her and this might help one to come to terms with one’s situation. Atteraya, Kimm, and Song (2014) asserted that the construct of women’s autonomy, which includes decision making power and freedom over personal affairs is an important aspect of autonomy. In addition, women’s autonomy has been empirically examined as the main predictor variable on health-related outcomes, such as health care utilization, pregnancy care, childcare, nutrition, HIV/AIDS knowledge, and behaviours. This implies that women, who are autonomous in making decisions about negotiating safer sex, thereby refuse to indulge in risky sexual behaviours, which are likely to have healthy sexual relations than those who lack the ability to negotiate for safer sex.

2.3. CONCLUSION

In this chapter, the researcher has thoroughly reviewed the information that is in relation with topic of interest. HIV/AIDS had been treated with a sense of emergency as it continues to be a major global issue. Interventions for prevention, care and treatment had been implemented and provision on ART had been accelerated according to the statistics on PLWHA accessing treatment. This has brought so much hope to PLWHA as this gives them hope of living an extended life even after diagnosis. Research states that there is still no cure for HIV/AIDS, but with the use of treatment, this disease can be managed. Despite this good news, PLWHA still face many challenges with the disease including the psychological aspect of their life, which has been neglected in the journey of making the existence of this disease bearable. Much effort and strategies have been implemented to enhance the life of PLWHA, but their psychological aspect has not been taken into account. According to research, the main factor that contributes to this agony is stress, which is caused by various aspects such as, the changes that occur, more especially in the bodies of PLWHA, which leave them unrecognizable due to the disease and the side effects of treatment. Another aspect mentioned in the research that is most challenging for PLWHA is poverty, whereby some people could not even afford food stability. All these aspects impact negatively on the state of mind of PLWHA, thus compromising their quality of life. It is against this background that the researcher considered it important to conduct this study on exploring the psychological well-being of PLWHA in Lusikisiki in the Eastern Cape, with a view to determining how they cope mentally, physically and socially with the disease.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

Flick (2014) defines research methodology as the systematic analysis of the methods that have been used in conducting research. Research methodology, however, does not set out to provide solutions; therefore, it is not the same thing as a method but sets out to offer the theoretical foundation for understanding which method be applied to specific cases. Research methodology is the common research approach which outlines the manner the researcher will commence with the research project. These methods outline the means of data collection or how a specific result is to be calculated. Research may either be qualitative or quantitative or a combination of both, known as triangulation (Flick, 2014). Research techniques and designs that have been used to gather and analyze the data of the study are presented in this chapter. Daniel and Sam (2011) state that it is of vital importance for a researcher to have a design for his/her research which is a blueprint for undertaking the research. Furthermore, this facilitates a smooth sailing of various research operations that enable the researcher to save time and resources. In addition, a researcher needs a research design for the advance planning of the methods to be used for accumulating the appropriate information and the procedures that have been used when that information is being processed and analyzed. They also mention that research design must be prepared in a careful manner because any error present might derail an entire project, as it has a great influence on the trustworthiness of the accomplished and this confirms without any reasonable doubt that it forms a firm foundation of the entire project.

3.2 RESEARCH PARADIGM

De Vos et al. (2011) assert that in the qualitative paradigm, the researcher is mainly concerned with the understanding of the naturalistic investigation, instead of controlled measurement, with the subjective investigation being taken from the perspective of an individual who is directly affected as compared to the one who is not. Killam (2013) mentions that the research paradigm is a set of opinions, which guides the research on how one views the world. Furthermore, it can be defined as a group of ideas or a manual on how a certain thing must be done. There are various types of research paradigms that include epistemological, methodological and ontological, however these research paradigms are discussed below.

3.2.1 Epistemological.

Killam (2013) argues that epistemology examines the relationship between the knowledge and the researcher during discovery, meaning that it refers to how we know what we know. Ritchie, Lewis, Nicholls, and Ormston (2014) state that epistemology is concerned with ways of knowing and learning about the world and focuses on issues such as how can one learn about reality and what forms the basis of one’s knowledge. Bryman (2016) mentions that an epistemological issue concerns the question of what is or should be regarded as acceptable knowledge in the discipline. Furthermore, in social sciences, a central issue is the question of whether the social world can and should be studied according to the same principles, procedures, and ethos of the natural science. In addition, the position that affirms the importance of imitating the natural sciences is invariably associated with an epistemological position known as positivism.

3.2.2 Methodological.

Killam (2013) asserts that methodology refers to the way we go about discovering knowledge in a systematic way. Furthermore, it is essential to remember that the research questions are the basis of qualitative research, therefore, the researcher needs to make sure that the research questions, conceptual framework, design, and methods agree. In addition, researchers need to be clear about how and why a particular design, method and data source will assist in addressing research questions rather than assuming that a particular one will be suitable enough to provide them with the information needed. He states that it is advisable for qualitative researchers, regardless of what they believe their practical restrictions are within the framework of their ontological and epistemological perspectives, to try to extend their scope by thinking extensively and creatively on the possible resources of data and methods to select and use.

3.2.3 Ontological.

De Voss et al. (2011) mention that for a researcher to further develop and implement the research topic into research design, it will depend on the way he/she believes that the research questions could be answered in the most truthful manner and his/her assumptions on how one should view the reality. Killam (2013) states that in research, ontology refers to what the researcher believes about nature, in reality, meaning and beliefs about what is true determines what can be acknowledged about reality. Ritchie et al. (2014) add that ontology is concerned with the nature of reality and to know about the world. Furthermore, an underlying ontological question concerns whether the social and natural worlds exist in similar ways or whether the social world is essentially different because it is open to subjective interpretation. Bhattacharya (2017) mentions that ontology refers to one's nature of being and it is precisely the force behind what motivates one to his/her actions and to his/her desire for the topic of one's intellectual investigation. Research perspectives include objectivism, constructionism, and interpretivism.

3.2.3.1 Objectivism.

Bryman (2016) argues objectivism is based on the belief that there is an external actuality that can be studied objectively and in this sense, objectivity refers to the ability to identify things as they really are. Furthermore, there are detailed methods that need to be pursued for this to be achievable as these methods will place the necessary check on subjectivity and damage personal judgment and emotions. In addition, methods play a significant role in enabling the researcher to identify the meaning that people bestow to their everyday life experiences in an objective manner. Walliman (2016) states that objectivism is the principle of social events and their meanings have an existence that is not dependent on actors, meaning that they are truths that have an independent existence. This study therefore, uses a constructionist view to understand the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape.

3.2.3.2 Constructionism.

Willig (2013) argues that constructionists believe that there is no truth out there but only a sequence of events of reality that constantly changes. He states that the main concern of research from social constructionist perspective is identifying a range of ways of building a social reality that exists in culture, by exploring the conditions of their use and tracing how they are implicated in human experience and social practice. In addition, a social constructionist perspective is often described as relativist because it eliminates the idea of objects, events, and even experiences that lead and enlighten our description of them. Furthermore, it exchanges the perception of description with that of construction because it argues that a language is a form of social action, which builds versions of reality for particular purposes. According to this view and in reality, it is the language or discourse that constructs reality rather than the reality that determines how we describe or talk about it. Bryman (2016) mentions that constructionism invites the researcher to consider the ways in which social reality is an ongoing accomplishment of social actors, rather than something external and totally to constraints them. Furthermore, constructionism suggests that the categories that people employ in helping them to understand the world around them are in fact of social products. In addition, these categories do not have built-in essences, instead, their meaning is constructed in and through interaction.

3.2.3.3 Interpretivism.

The researcher employed interpretivism as a research paradigm for the present study as she is depending on the information the participants will provide on how they see and interpret their world through discourse. Brynum (2016) states that interpretivism believes in the assumption that reality should be translated through the meaning that respondents furnish to their world and this meaning can only be determined through language. Walliman (2016) claims that interpretivism is the acknowledgment that subjective meanings play a central role in social actions as it aims to expose interpretations and meanings. In addition, taking an interpretive stance can mean that the researcher may come up with astonishing findings, or at least findings that appear shocking from a stance outside the particular social context studied. O'Reilly and Lester (2017) assert that human interpretation is the first point for the invention of knowledge of the social world. Furthermore, from the tradition of interpretivism, an individual's subjective interpretation of reality affects his/her position on reality, which is why it is of vital importance that one needs to better understand how people experience, feel and identify their own social world if they better determine the meanings for the behaviour of individuals and their inspirations for them. This study is about the psychological well-being of PLWHA and the researcher tried to get into the understanding of the participants' world of living with the disease. According to the interpretive approach, the researcher makes meaning from the interpretation of the interactions of the participants with regard to the experiences; hence the researcher becomes the participant observer in the phenomenon (O' Reilly & Lester, 2017).

3.3 RESEARCH APPROACHES

Creswell and Creswell (2017) refer to research approaches as strategies and processes that cover the steps from comprehensive beliefs to exhaustive methods of collecting and analyzing data. They further state that selecting a research approach is based on the nature of the research problem that will be addressed, the personal experiences of the researcher and the audience of the study.

3.3.1 Qualitative approach.

The researcher employed a qualitative approach to research in the current study and De Vos et al. (2011) establish that it allows one to have a better and more compound insight of information in an anticipated study while analysis is strengthened when data is interpreted. Furthermore, the qualitative research concentrates on how individuals and groups observe the world and construct the meaning out of their experience. In addition, using qualitative research is advantageous as it is flexible as it does not present a systematic plan to the researcher, that is, it is not a linear process and has no fixed design. It presents the researcher with total freedom to let the study unfold naturally and provides a variety of ways to examine the information. De Vos et al. (2011) mention that, in qualitative research it is of utmost importance that the researcher gives a comprehensive report of the process of data collection to how it was vigorously analyzed in order to make sure that other researchers could replicate the study. In addition, to knowing exactly what the researcher did and how he/she went about collecting and analyzing data.

3.3.1.1 Descriptive research.

Chawla and Sondhi (2011) mention that descriptive research as the name, implies, aims at exposing the data and primary characteristics about the object or situation under study, which is undertaken to describe the situation, community or phenomena. Furthermore, it is current, relevant and time-bound and it tackles the establishment of a formulated proposition. In addition, descriptive research is conducted to test specific hypotheses and trends. They also state that descriptive research is more structured and involves a formal, specific and systematic approach to sampling, collecting information and testing the data to confirm the research assumptions. They claim that the findings of descriptive studies are mostly of a diagnostic nature, that is, the studies indicate the existing symptoms of a particular situation without establishing the causality of the relationship. This study is descriptive in nature as it provides descriptions, interpretations, and experiences of the participants from their personal view. Thus giving the researcher an ability to reflect on his/her experiences based on the findings of the study.

3.3.1.2 Contextual research.

Privitera (2015) asserts that in the contextual inquiry, the researcher carefully observes and possibly has a conversation with the user in a casual manner, while the user is performing the task that the researcher has an interest in by collecting the facts and taking field notes. Nunnally and Farkas (2017) mention that contextual inquiries are the most frequent account of discovery and exploration and they are the study of how people perform one or more tasks within the context. Furthermore, the goal of contextual inquiries is to be present, though one might not be noticed and observe with as little intrusion or bias as possible. In addition, these inquiries start with promptness of participants' thinking aloud about what they are doing, which provides the context of actions as well as immediate, observable feedback on their tasks. They further state that researchers probe, asking questions of the participants to gain a deeper understanding. Also, the contextual inquiries rely on trends and the experience of the researcher and ability to make judgments about what is important. Furthermore, the rule here is that when the researcher hears the same information repeatedly, he/she has conducted enough research. This study is contextual in nature, the researcher had to understand the language and presentations recorded of PLWHA without infusing her ideas and thoughts about the topic under investigation.

3.3.1.3 Exploratory research.

Saunders, Lewis, and Thornhill (2012) assert that exploratory research's main intention is merely exploring the research questions and does not intend to recommend the exact resolutions to the identified problems. Furthermore, it is carried out to establish the makeup of the problem. In addition, exploratory research facilitates one to understand the problem better as it does not provide definite proof. Saunders et al. (2012) also mention that the researcher must be determined to change his/her course when new data and insights are revealed during the process of conducting exploratory research. Chawla and Sondhi (2011) establish that exploratory research allows the researcher to gain a better understanding of the concept and provides direction in order to commence with more structured research. Furthermore, exploratory studies are also conducted to develop, refine or test the designed measuring instrument. In addition, studies of this nature are less structured, more flexible and are performed to test or validate any preconceived propositions. Chawla and Sondhi (2011) also state that exploratory research could lead to some testable hypotheses and some schools named them the pilot or feasibility studies. They further establish that it is the first step that is taken by the researcher into the unknown to explore new borders, which establish whether a full-scale exploration is advisable. This study further employed the exploratory research, as the psychological well-being of PLWHA has not been widely explored in Lusikisiki area so that one can understand the everyday experiences of these individuals as they move ahead with life.

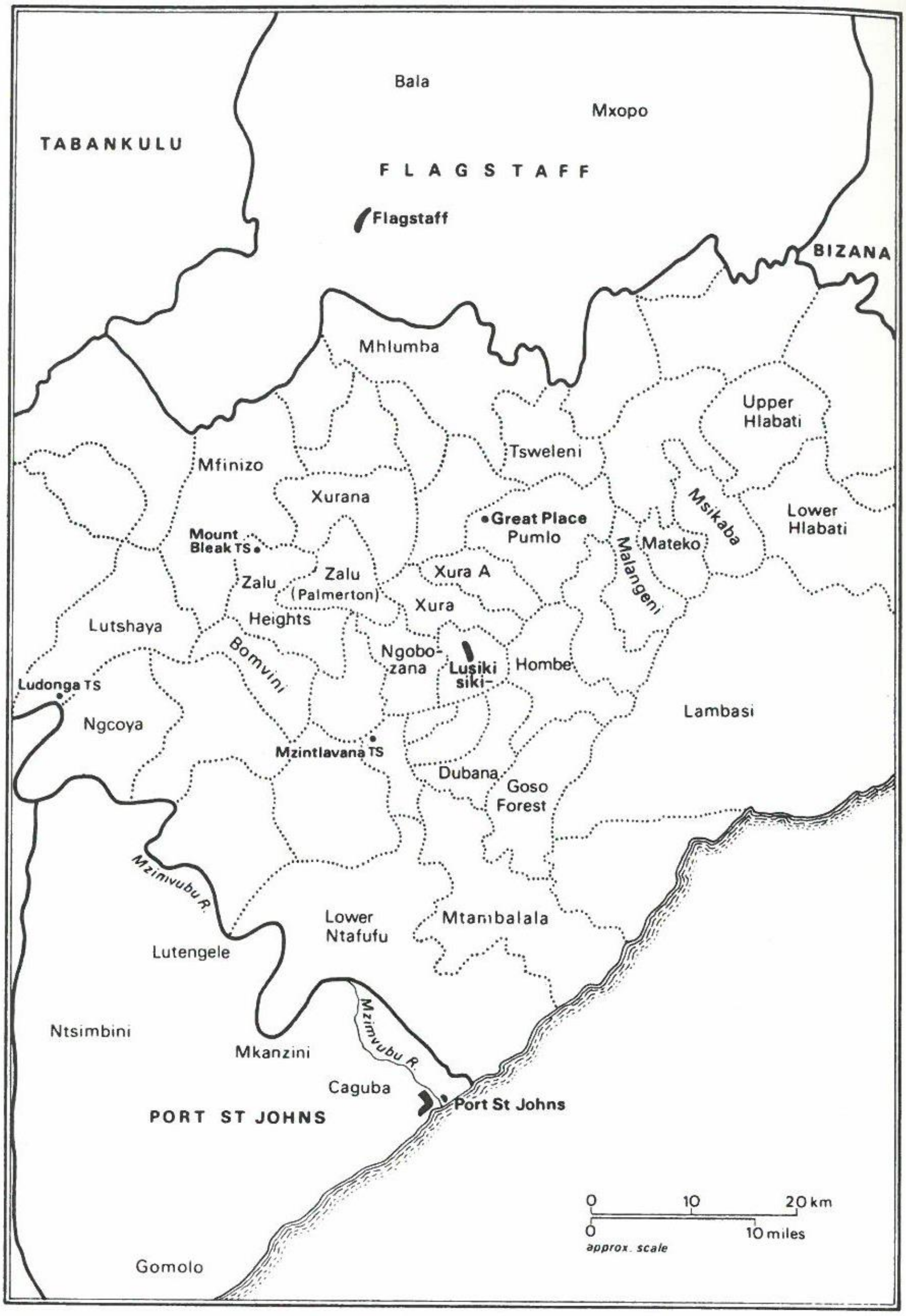
3.4 POPULATION AND SAMPLING

Creswell and Creswell (2017) state that whatever phenomenon one wishes to clarify, one ought to explain it by collecting relevant information from the real world, and use that information to draw conclusions about what is being examined. They further state that there are various methods and techniques used for sampling. The researcher considers only the information from a subgroup, rather than all possible cases or elements of the entire population known as sampling. According to Leavy (2017), sampling is “a tool that enables one to draw conclusions about the characteristics of the population, after studying those objects that are only included in the sample”. Leavy (2017) states that a sample is ‘a smaller representation’ of the total population, while a ‘sample design’ refers to the course of action the researcher would implement when selecting items for the sample, which may also determine how many items will be included known as the sample size. Furthermore, there are various types that one could pick from and some are more accurate and easier to use than others. This is why the researcher needs to select a sample design that is dependable and suitable for his/her study.

For the present study, the researcher used non-probability sampling, which means that individuals in a population did not have an equal possibility of being chosen to be participants, however, purposive sampling is specifically used for this study. Purposeful sampling as the name implies refers to a sampling method by which participants of the sample are chosen on purpose. This technique implies that a specific case is chosen because it possesses some features that are of interest for that particular study and in this study that feature would be living with HIV/AIDS (De Vos et al., 2011). The researcher only considered people living with HIV/AIDS (PLWHA). Regardless of their marital status, the researcher collected the data by interviewing 15 individuals (male and female) living with the disease regardless of when they were diagnosed and they fall within the ages of 18-60 years. Having communicated the population and the sampling, site for data collection will be discussed.

3.4.1 Site for data collection.

The site for data collection is located in Lusikisiki, a town in the Ingquza Hill Local Municipality in the Eastern Cape Province, South Africa. The name results from the rustling sound of reeds caused by blowing wind in a nearby river and this was named by the local AmaMpondo people. The site is situated about 45 kilometers inland from and North of Port St. John's and is positioned along R61 leading to Kokstad (Wikipedia). The site for the researcher's data collection was a Treatment Action Campaign District office that is situated at the Embassy Building, Jacaranda Street in Lusikisiki. The following is the map that represents the location of the Treatment Action Campaign district office.



3 Sketch map of locations in Lusikisiki district for identification of place of residence of oral informants (1976/7). TS = Trading Station.

Figure 2. Map of Lusiksiki by Benairt, 1982

3.5 DATA COLLECTION TOOLS

Bryman (2016) mentions that data collection tools are means or ways to conduct a study. However, the conduct of research could only be justified through the methods and techniques that are meant for it, which then assist in analyzing the responses of the population on related variables by a careful interpretation of a sample. The researcher had used various research tools that will be discussed below.

3.5.1 Individual interviews.

The researcher had used individual interviews where she conducted in-depth face-to-face interviews with each individual. This was done to explore the views, experiences, beliefs, and motivations of each individual as an interview is believed to provide a deeper understanding of a social phenomenon. The researcher conducted individual interviews to allow each participant to freely express themselves about their individual experiences regarding living with HIV/AIDS, which would be difficult to do so in a group setting because of the sensitivity of the topic.

3.5.2 The type of interviews and interview schedule.

The data for the current research was collected through interviews, and the in-depth semi-structured interviews were specifically used. Brinkmann (2014) defines an interview as a spoken conversation between the researcher and the respondent with the aim of gathering relevant and significant information for the study. Each participant was to foremost answer the questions on the first section of the questionnaire, which contained the bibliographical details of each participant before going to the second section with open-ended questions. An interview guide was used to keep in track the important themes that needed to be covered in the interview (Raworth, Sweetman, Narayan, Rowlands, & Hopkins, 2012) (see Appendix A). The interview guide used was composed by the researcher and was inspired by the research topic and research questions.

3.5.3 Advantages of semi-structured interviews.

Semi-structured interviews were used because they could be prepared ahead of time which allowed the researcher to be prepared during the interview. The choice of semi-structured interviews offers sufficient flexibility of approach to different respondents, while still covering the same areas of data collection. Semi-structured interviews also allow the participants to be free when expressing their own views using their own terms, thus providing the researcher with much more information that was not expected to be gained from the participants. They also provide reliable, similar qualitative data as the researcher is able to acquire a more personal encounter with the source of information as compared to other sources of data collection like questionnaires. Semi-structured interviews also allow the researcher to probe further to get more information as some of the questions were personal (Galletta, 2013).

3.5.4 Procedures of data collection.

Firstly, the researcher applied and was granted permission to conduct research by the Ethics Committee of the University Of Fort Hare. Permission was specifically sought from the Dean of research at the University. The researcher also asked for permission from the necessary gatekeepers as a measure to ensure that the researcher operates within the boundaries of the research ethics. For this reason, the researcher went to submit a letter from the University (see appendix B) to the Treatment Action Campaign district office in Lusikisiki in order to ask for permission from the relevant authority to conduct the study. This was in line with Glaser and Strauss (2017) who asserted that it is critical to ask for permission from gatekeepers before any contact is made with the participants of research.

On that day, the researcher only submitted the letter and was given an appointment for another day as the people there were busy with training. On the set date, the researcher went back for the response and was assisted by the supervisor, who then gave her the permission to collect the data after answering a number of questions. On arrival, the researcher introduced herself and stated why she was in the office, which was the collection of data for her study with the topic ‘The exploration of psychological well-being of People Living with HIV/AIDS in Lusikisiki, in the Eastern Cape, South Africa’. The supervisor had a series of questions directed at the researcher and the first question was, what the researcher knew about TAC and the reason for conducting the study specifically in Lusikisiki. This was not a difficult question for the researcher because she knew that in the TAC office, people usually gather there for many purposes, such as training and organizing outreach programmes and treatment action campaigns for the community at large, though the main aim for the office is Prevention and Treatment Literacy and Community Health Advocacy, where PLWHA attend to be taught about the Antiretroviral Therapy and how to handle HIV/AIDS as a disease.

The reason the researcher chose Lusikisiki was because Lusikisiki is my hometown and she was concerned about the circumstances of PLWHA in that area because of its rurality with poor living conditions, and lack of resources such as health facilities and doctors. The supervisor at the office had an issue with the fact that researchers from various institutions had been conducting their studies and they had been assisting them with data collection over the past years. The supervisor however, told the researcher that they have never benefited from those studies and they were at the verge of not assisting researchers anymore, because of not getting anything in return, hence, they saw those studies as a waste of time for them. The supervisor, as well complained that even government had not done anything after providing PLWHA with treatment, like monitoring how they were doing. She said PLWHA reported that they were tired of taking the treatment, which requires them to do so for the rest of their lives. The researcher tried to explain to the supervisor that even though she was a researcher, she was still in school and at that moment there was nothing to promise except for the fact that she, as the researcher just came for assistance in order to complete her dissertation, which is a requirement for the completion of master's degree. The researcher however promised to help during vacations as she has nothing to do, as well the researcher promised that the recommendations of the study will be provided to the TAC supervisor so that they can gain a better understanding of what is going on and how the participants have responded. The supervisor was adamant for a moment, but eventually granted the researcher permission to collect data. She then told the researcher that she would refer her to one of the support groups and she suggested the one at the researcher's own administrative area for easy access. The supervisor looked at her diary and gave the researcher the date for meeting the support group, in order for the supervisor to introduce the researcher to the members.

On the chosen day, the researcher came in a little bit earlier and the supervisor was already there though members of the support group were still coming in. When the members were in full attendance, the programme commenced with an opening prayer, then everyone introduced him/herself. After the personal introduction of the members, the supervisor then introduced the researcher to the group explaining to them precisely why the researcher was there. She then handed over to the researcher to carry on with what was expected of her. The researcher greeted the members and went straight to the point of telling the members that she was a student of the University of Fort Hare and requested for their participation in a study the researcher was conducting regarding PLWHA. The researcher explained the aim and objectives of the study to the members and that 15 participants were required preferable 8 females and 7 males. She also mentioned the ethical considerations involved in conducting the study that are explained later in this chapter. The researcher asked that if there was anyone who was willing to assist, he/she might come and talk with her after the meeting for further clarifications. After the gathering, people came and gave the researcher their contact numbers so that she could schedule an appointment with them for the interview sessions.

3.5.5 Data collection processes.

During the course of that week, the researcher started contacting the individuals and they were willing to meet and most of them wanted the researcher to meet them at their homes where there was privacy without any disturbances. Within the interviews, IsiXhosa language was used as the medium of communication, as the guide to the questions was also written in

IsiXhosa in order to allow the participants whose mother tongue was IsiXhosa, to clearly understand the questions asked and to better express themselves. Interviews were also audio-recorded for those participants who granted the permission to be recorded, and the researcher made sure that the cellular phone she used for recording was working before commencing with each interview process. Audio recording allowed a fuller record of participants' responses than field notes taken during the interview and the researcher could concentrate on other aspects, such as the non-verbal gestures including, laughter, pauses and silences, which were integrated into the final write up to present a clear picture of the view and how the participants felt or reacted during the interview.

The researcher ensured that the participants were comfortable before beginning and during the course of the interview. The researcher initiated the process of interviewing, by first introducing herself to the participants, while appreciating them for taking their time and agreeing to be part of the study. The researcher then went on and explained about informed consent and what it meant in the context of the current study, and it was only after these explanations to the participants who showed interest that they were given the opportunity to voluntarily sign the consent forms (see Appendix C). The purpose and significance of the study were also recapped to the participants before beginning of the interview. The researcher would first explain to the participant that she, the researcher would ask some questions and the participant would be open and honest in providing answers, as well as given the freedom to ask for clarity if any participant does not clearly understand the question. Before starting the interview, the researcher first read and clarified the questions to the participant for a clearer understanding. After each interview, each participant was appreciated.

Monette, Sullivan and DeJong (2013) asserted that the capacity and the value of information exchanged during the process of interviewing depend on how perceptive and innovative the interviewer is, at identifying with and handling the relationship with the participant. The researcher administered individual interviews herself so that she might be in control of the environment and to put herself in the shoes of the participants so as to have the emphatic understanding of the participants' feelings. While the researcher was administering the interviews, she took full advantage of observing first-hand, the behaviour and the body language such as verbal and non-verbal cues of the participants. When the responses were not satisfactory, the interviewer kindly asked the participant to elaborate more and clarify the answer (Flick, 2014). Each interview was about 45-50 minutes.

3.6 DATA ANALYSIS

Siu and Comerasamy (2013) established that qualitative data is often based on and influenced by personal feelings and opinions that consist of profound information presented in the form of words. Analyzing it demands reading a large quantity of text, looking for similarities or differences and consequently finding themes and developing categories. In qualitative research, there are a wide variety of methods used for data analysis, such as content, thematic or discourse analysis. The researcher used thematic analysis, which is the most commonly used form of analysis in qualitative research. It puts emphasis on identifying, examining and recording patterns or themes within data. These are patterns across data that are essential in the description of an observable fact and are connected to a specific research question. In the thematic analysis, transcribed texts are broken down into units of meaning; units of meaning are placed into categories; themes are systematically identified; when collected, these themes will give insight into the issue being studied. Themes are picked through the interviews and discussions (Siu & Comerasamy, 2013).

The thematic analysis required the researcher to become familiar with the data collected by first browsing through all the interview scripts as a whole and making notes on the first impressions the researcher had about the data. The researcher then re-read the transcripts again one by one and very carefully line by line. The researcher started labeling relevant words, phrases, and sections that could be about actions, concepts, differences, opinions, and processes. The researcher labeled those concepts when they were repeated in several places or if it was a captivating idea or the interviewee explicitly stated that it was important. The researcher also labeled those concepts that she had read something similar in the literature review or when she was reminded of a certain concept or theory. The researcher repeatedly went through data collected from the interviews and field notes, while observing the underlying meaning of what she observed and recorded when the interviews were conducted. This therefore, helped to develop themes and highlights found within the interview. The audio recordings were played and replayed in order to familiarise oneself with data collected. The researcher needed to be considerate to words and phrases used by the participants that captured the gist of what they said.

After coding, which was done by labeling relevant words, phrases, sentences and sections, the researcher had plenty of codes, thereafter decided which were the most important codes and brought them together to create themes out of them. The researcher did this by going through all the codes and read them with a coloured pen at hand and highlighted those two or more codes to make each theme. The researcher dropped some of the initial codes and kept only those that she thought were important and grouped them together. After the themes were created, the researcher labeled them and kept those she thought were relevant and were connected to each other. These themes and the connections were the main result or core of the study. It was a new knowledge about how the participants saw their world. The researcher, under the topic of data presentation then, described the themes and how they were connected using a neutral voice and not interpreting the results. After that, the researcher wrote out her interpretations and discussed her results. The following ethical considerations were taken during data collection.

3.7 ETHICAL CONSIDERATIONS

According to Babbie (2014), ethics entail moral values that dominate a person’s behavior or conducting of activity, being obedient to a code of principles, the regulations of conduct, the responsibilities of the researcher and the standard of conduct of a given profession. Ethics are therefore very important in research as they protect the public from exploitation, physical as well as psychological harm. The researcher applied for and was granted the Ethical clearance certificate (attached) from the University of Fort Hare Research Ethics Committee before conducting the study. In the present study, the researcher acknowledged the following ethical issues during the process of working and collecting information.

- Welfare of participants
- Informed consent
- Voluntary participation
- Confidentiality and anonymity

3.7.1 Welfare of participants.

The researcher was committed to making sure that there was no harm instigated in any way on those that participated in the research. The researcher gave the participants full information regarding their involvement in the study. She ensured the participants that whatever information acquired from them about how they cope physically, socially and psychologically while living with the disease, would be treated with privacy and pseudonyms were used in the place of their real names. In the process of interviewing the participants, the researcher stopped when participants felt any form of discomfort or when they felt that they were not able to continue with the interview. After going through the welfare of participants, informed consent was discussed.

3.7.2 Informed consent.

Respect for other people entails that participants be given the freedom to choose what was to happen during the interview. Gaining informed consent entailed that all possible information on the aim of the study, the expected duration of the participant’s involvements, information on their right to ask to be excused, anticipated consequences of withdrawal, potential discomfort, prospective research benefits and the processes which were to be followed during the investigation be provided to potential participants (Flick, 2014). During the research, the participants were informed as they had a right to know what the research was all about, how it would help them and how it would affect them. The participants signed consent forms that provided them with detailed information on the study so that they could make informed and voluntary choices to participate. Although the consent was written in English, it was also translated to IsiXhosa in a reasonably understandable manner. Having looked at the informed consent, voluntary participation was discussed.

3.7.3 Voluntary participation.

Flick (2014) asserted that participating in research should be one’s willingness to participate at all times and no one should be forced to take part in the study. Participation in this research was voluntary as no participant was coerced to be part of the research. Participants were encouraged to talk about their stories only to help raise awareness on the issue and to look at ways to cope with the challenges they face. After communicating voluntary participation, confidentiality and anonymity was discussed.

3.7.4 Confidentiality and anonymity.

Confidentiality entails that all the information acquired from the participants should be kept private and safe from any other person who has no right to have access to it. Anonymity means that no one, including the researcher, should be able to identify any participant afterward (Flick, 2014). The researcher did not struggle to maintain the anonymity of the participants’ identity throughout the study as only pseudonyms were used. Participants were not required to write their names and their identifying information on the bibliographical questionnaire. The researcher's concern was to protect the interests and well-being of those who participated in the study (De Vos et al., 2011). After the researcher was through with the articulation of the ethical considerations taken, the trustworthiness of the study was discussed.

3.8 TRUSTWORTHINESS

The researcher conducted the study which was carried out fairly and ethically and whose findings signify and display the experiences encountered by the participants. The following are the four key elements that are included in criteria for determining the trustworthiness of qualitative research, which are credibility, dependability, confirmability, and transferability (Moule & Goodman, 2013). The first element of credibility was discussed.

3.8.1 Credibility.

Marshall and Rossman (2016) state that credibility plays a role to a belief in the trustworthiness of data through the following attributes: lengthened engagement; constant observations; triangulation, referential sufficiency, peer debriefing and member checks. They further state that the major and generally used techniques to address credibility are triangulation and member checks. The researcher separately asked the participants the same research questions, collected information from various sources and used diverse methods to answer those research questions and that process is called triangulation. Member checks were also carried out whereby the researcherasked the participants to review both the data collected during the interviews and the researcher's interpretation of the interview data.

Participants were appreciative of the member check process as it gave them assurance that whatever has been interpreted by the researcher was what they had given as answers during the interviews and that also gave them a chance to fill in any information they might have left out from the earlier interviews. Furthermore, trust is an important characteristic of the member check process. The study was carried out in such a manner that the subject was accurately established and portrayed as the researcher interacted directly with the affected individuals who knew exactly what they were talking about as they were the ones who were experiencing the challenges. Having communicated credibility, transferability was discussed.

3.8.2 Transferability.

Court (2017) asserts that transferability is a process of making the findings of the study apply broadly to other situations and contexts. It is not regarded as a practical naturalistic research objective. The background by which one collects and organise qualitative data contributes when data is interpreted. Court (2017) adds that it is for these reasons that generalization in qualitative research is restricted. Purposive sampling that consisted of people living with HIV/AIDS in this case, had been used to address the issue of transferability since specific information had been maximized in relation to the context in which the data collection occurred. This type of sampling required the contemplation of the features of the individual members of the sample in as much as those features are directly linked to the research questions. Transferability in the study was done by thoroughly describing the research context and the assumptions that were central to the research by the researcher. After credibility, the researcher discussed another element of trustworthiness of the study which is dependability.

3.8.3 Dependability.

Guest, MacQueen, and Namey (2012) establish that in order to address dependability more directly, the procedures within the study need to be stated in detail so that whenever other researchers want to repeat the work, they should be able to do so and also come up with the same results. They further state that such in-depth exposure also permits the reader to weigh up the degree to which appropriate research procedures have been followed. Readers of the research report are then enabled to develop a comprehensive understanding of the methods and their usefulness. The researcher interviewed the respondents for the second time just to be sure that she got the same answer as the first time. Where there were changes that occurred in the setting, the researcher described those changes as it was her responsibility to do so. Confirmability was then discussed which is the last element in the trustworthiness of the study.

3.8.4 Confirmability.

Bloomberg and Volpe (2012) state that confirmability refers to the degree to which the results could be confirmed by others. This has to do with the level of confidence that the research findings were based on the participants' narratives and words rather than potential researcher's biases. Confirmability was there to verify that the findings were shaped by participants more so than they were shaped by a researcher. The researcher ensured confirmability by looking at each question with each respondent to check if what was recorded was being confirmed and if it was indeed the response from that particular respondent.

3.9 CONCLUSION

This chapter gives the readers a clear direction on how the study had been conducted. It shows the research design that was used, the population and sample group that formed part of the study, the research techniques that were used and how the data was collected and analyzed. It also shows the steps taken in order for the researcher to confirm that the ethics were considered and applied in an appropriate manner while working with the participants. The following chapter will present the results of the interviews conducted.

CHAPTER 4: DATA PRESENTATION AND ANALYSIS

4.1 INTRODUCTION

This chapter describes qualitative data presentation and analysis that the researcher gathered from support group members in Lusikisiki. Data collection was performed through in-depth semi-structured interviews with the use of interview guide. Each interview guide consisted of two sections, the first part contained details about bibliographical information of each participant and the second section contained open-ended questions. The researcher interviewed fifteen PLWHA and they all spoke IsiXhosa.

4.2 DESCRIPTION OF PARTICIPANTS

4.2.1 Participants.

From the fifteen participants interviewed seven were males and eight of them were females. Naidoo, Chirinda, Mchunu, Swartz, and Anderson (2015) stated that both males and females are infected by the HIV/AIDS pandemic, while HIV prevalence is higher in women than men as more than half of all infected people worldwide are women. Furthermore, women are regarded as being at higher risk of being affected by HIV, due to gender inequalities as they do not have the authority to negotiate safe sex. In addition, the key social drivers of HIV vulnerability among young women in sub-Saharan Africa are factors such as unprotected sexual encounters with multiple partners, insufficient comprehensive knowledge on how HIV is transmitted and prevented, as well as poverty, which is the paramount reason why women are mostly at high risk of HIV infection in society. Naidoo et al. (2015) further urged that women of lower economic status have a history of being abused, meaning that they are disempowered in sexual relationships. These women endure whatever treatment they get even if it jeopardizes their health from the men they are dependent on for their survival. This compromises women’s ability to choose harmless and healthier life approaches. Furthermore, there is evidence that many new cases of HIV infection are the result of gender-based violence in homes, schools, the workplace, and other social settings. Tarimo et al. (2018) argued that high numbers in global developments are the evidence to the result of this phenomenon, whereby more women and girls get infected with HIV/AIDS yearly particularly in the low-income countries. In this study, there was almost the same number of males and females suggesting that some males in Lusikisiki area get tested and live positively with HIV/AIDS hence participating in the support group. This is not in agreement with the findings by Masenya and Mtshiselwa (2016) that women are the only ones who are hit hard by the pandemic of HIV/AIDS in Africa and that males living with HIV/AIDS do not attend support groups with females.

Seloilwe and Thupayagale-Tshweneagae (2015) argued that women who experience intimate partner violence which often takes place as part of forceful control because of power differences in relationships, find it difficult to negotiate condom use. Ramjee, Moonsamy, Abbai, and Wand (2016) established that in South Africa alone, it is reported that more than 100 000 infections occur in young women each year, which is more than four times the number of new reported HIV infections estimated to occur in adolescent and young men. They further mentioned that the Province of KwaZulu-Natal in South Africa is the region most affected by HIV/AIDS and women account for more than 60% of infections.

4.2.2 Age of participants.

The age of the participants for the study ranges from age of 18 years to 60 years with two in the 20 to 30 age cohort, six in the 30 to 40 age cohort, five in the 40 to 50 cohort and two in the 50 to 60 age cohort. In this study, there is a small increase in the age ranges of 30 to 40 and 40 to 50 of PLWHA. These are reproductive ages for women and from the interviews, it was asserted that it is when these women got pregnant that they were diagnosed (Mbulawa, Coetzee & Williamson, 2015). This is in contrast with Seloilwe and Thupayagale-Tshweneagae (2015); Naidoo et al. (2015) who established that the growing concern is on young girls who are in relationships with older males partners for financial motives, as they have no choice in making decisions about using protection during sexual encounters as compared to when they are in relationships with males of the same age. In addition, these male partners have a greater influence on sexual decision making as an outcome of gender-based violence and power imbalances in these relationships. Mbulawa et al. (2015) emphasized that the peak in women is between 25 and 29 years while in men it is between 30 and 34 years of age. In South Africa, women are more likely to have sexual partners who are four years older than themselves. Ramjee et al. (2016) mentioned that one of the key population groups with high reported HIV incidence is the adolescent girls and young women of between 15-24 years of age who contribute to almost one-third of all new reported HIV incident infections.

4.2.3 Marital status.

Out of the fifteen participants, nine were single, three were married, two widowed and one divorced. These results suggest that single participants are the most affected in the sample, followed by the married participants, two widowed and one divorced. Ramjee et al. (2016) asserted that in South Africa, women who are not staying with a stable partner those who are either cohabitating or not married face more danger of HIV infection as compared to women who are married. Furthermore, these unmarried women are exposed to structural factors, such as migration, transactional sex for economic survival, gender norms and urbanization, which in turn are contributory factors that further strengthen their vulnerability. They further mentioned that the analysis of the relationship between marital status and HIV showed that high incidence for married participants living together was lowest as compared to all other marital status groups. Furthermore, the HIV incidence rate for those who were in a relationship and going steady with their sexual partners was greater than the HIV incidence rate for those married living together. In addition, the HIV incidence rate for those who were single, widowed or divorced was greater than the HIV incidence rate for those married and living together.

Shisana et al. (2016) claimed that individuals who were married and living with their spouses were considered to have lessened chances of being HIV-positive. They further stated that low-socio-economic status combined with poor living conditions in informal areas may result to an increased risk of HIV among unmarried populations. In addition, with decreasing marriage rates and poor economic conditions, messages should be targeted for unmarried and cohabitating people and that living together unmarried carries the highest risk among all marital statuses in South Africa.

4.2.4 Level of education of the participants.

Out of fifteen participants two had primary education, nine with secondary education and four with tertiary education. Leon, Baker, Solinas, and Henck (2017) established that it has not been clear on whether the level of education has an influence on acquiring HIV or not. They further mentioned that in earlier years of the HIV pandemic, epidemiological studies identified that adults who were learned in Sub-Saharan countries had a higher risk of contracting HIV than those who were uneducated. They mentioned that later in the pandemic, it was established that educational attainment, occupation, and income is not associated in any way with the likelihood of one being HIV-positive as anyone could be affected. Harling and Barnighausen (2016) asserted that individuals who are more educated tend to have more income, thus having more control over their lives and ability to act on knowledge. Furthermore, these people also have high hopes for their future and they place a higher value on those hopes, which is why they are more motivated to take preventative measures to secure their future.

4.2.5 Socio-economic status of participants.

Out of fifteen participants, two were self-employed, five employed and eight unemployed. From these results eight participants were unemployed and HIV/AIDS tends to thrive where there is poverty. Liu et al. (2013) asserted that employment plays an important role in the well-being of PLWHA as it enhances one’s self-esteem, life satisfaction and personal identity. Furthermore, employed PLWHA significantly reported better quality of life than those who are unemployed and there are many of them in South Africa due to high levels of unemployment. Mamboleo (2017) established that employment has been recognized as a key social cause of health for PLWHA in society. Furthermore, in comparison to unemployed persons with HIV, disease severity is lower in persons who are employed. In addition, unemployment, underemployment and job dissatisfaction may be damaging to the health status of PLWHA as unemployment results in unfavourable effects on psychological well-being and the quality of life of individuals, due to the fact that one feels worthless, lonely, financially limited and has poor standard of living.

Mamboleo (2017) argued that unemployment reduces external stimuli necessary for nurturing neurocognition in PLWHA because the ones employed are engaged cognitively and socially. Furthermore, this engagement enables individuals to learn new skills, which lead to their memory and cognition being improved. In addition, as PLWHA experience neurocognitive degeneration and age with the virus, employment can be regarded as a protective factor for this population. Mamboleo (2017) also stated that work stress may, however, result to the speeding up of HIV progression, on the other hand, which is why counselors must be willing to help PLWHA cope with work-related stress in their respective workplace. However, in Lusikisiki employed PLWHA did not report any stress related to work. Mamboleo (2017) further commented that reported advantages to employment include economic self-sufficiency, improved self-esteem, enhanced social engagement, reduced physical pain, improved self-perception of physical and mental health and enhanced vigour and liveliness.

4.2.6 Income levels of participants.

Out of fifteen participants, seven lived under R1500 per month which is a level of social grant in South Africa. Four participants earned between R1500 to R3500 while four earned above R3500. It is interesting to note that seven participants earned below R1500 and this represents a high number of participants. This suggests that participants in the study were living under dire circumstances. Even those who are employed earned between R1500 and R3500 and only four of the participants earned over R3500. In looking at these income levels, it is evident that the Eastern Cape Province is among the poorest provinces in South Africa. The Statistician, General Pali Lehohla in a newly-published Poverty Trends Report mentioned that the Eastern Cape Province remains the poorest Province in South Africa, whereby 36% of the households in the Province survived on social grants as their main source of income. In addition, as compared to other Provinces, Eastern Cape had the highest percentage of poor households with children receiving child support grants (Dapia & Mpongwana, 2018).

Jennings et al. (2017) stated that being in financial distress may include being in debt, not having a stable income, earning a low income, not having enough food, which is linked to higher rates of engaging in unsafe sexual encounters, not using condom consistently and having multiple sex partners. Ngwenya, Gumede, Shahmanesh, McGrath, Grant, and Seeley (2018) mentioned that people become vulnerable to HIV infection because they do not have economic independence. Therefore, they have no sense of control over their lives and they lack the ability to change behaviour. Probst, Parry, and Rehm (2016) asserted that in South Africa low-socio-economic status is linked with reduced food security and lower food diversity with an increased possibility that some people might skip meals and go hungry which is a chief obstacle to adherence to treatment. In addition, generation of immune cells is greatly dependent on various nutrients found in food.

4.2.7 Dependants

Out of fifteen participants, four have no children, two participants have one child while two have two children, four have three children, two have four children and one has five children. The number of children per person living with HIV/AIDS has does not determine one's status as four of the participants have no children. The researcher could not find any literature that explains extensively how a number of children a person has might be connected with one being infected with the disease. Although no studies are related to HIV/AIDS and the number of children one might have, research suggests that high numbers of children could increase the population of people in a household and with low earnings predisposing families to poverty.

4.3 DISCUSSION OF THEMES

In this second part of data analysis, a number of themes were identified namely: unemployment, disclosure, healthy lifestyle, support systems, empowerment programmes, coping strategies, self-acceptance, personal growth, autonomy, purpose in life and environmental mastery which are discussed below.

4.3.1 Theme 1: Unemployment

Unemployment appeared to be the most common factor among PLWHA as eight of the participants were unemployed and they depended entirely on child support grant. Five participants were employed and two were self-employed. Given the fact that most of the participants are unemployed, this has a negative impact on their way of life because they lack the basic needs such as food.

A very concerned and a sad unemployed female participant mentioned:

"Heeeeyy… where do I start? My wish would be for the government to assist us financially so that we could at least have a decent place to stay and be able to buy food which will boost the medication" (Miss L., Aged 42).

Another unemployed participant stated:

> *"Mhhhh...If the government can assist us in ways in which we can be able to have an income in order to survive as we are not working.*
>
> Raising her voice a little and putting an emphasis using her hands she further stated:
>
> "*We are willing to start community projects, such as growing chickens and planting vegetables for making a living and for our own consumption, but no one is willing to assist us with funding to start those. In the past, PLWHA were given a disability grant when one was in a certain stage of the disease, but that has been stopped completely and that grant was helping in a big way"* (Miss N., Aged 37).

The above responses are in line with Gebremichael, Hadush, Kebede, and Zegeye (2018) as they mentioned that HIV/AIDS thrives mostly where there is lack of employment as employment gives dignity, sense of satisfaction and independence. They argued that PLWHA lack access to nutritious foods, which makes the challenges to the success of ART worse. Austin, Choi, and Berndt (2017) mentioned that there is a link between unemployment and socio-demographic factors. Furthermore, a poor educational level has been recognized as the primary socio-demographic risk factor for unemployed PLWHA. This was evident in Lusikisiki where eight of the participants were unemployed and some with a low level of education. Gebremichael et al. (2018) further mentioned that the impacts of HIV/AIDS combined with food insecurity, put more pressure on the household resources that are already limited, as the affected family members struggle to meet their needs. In addition, starvation and food insecurity are linked with escalated death rate and poor clinical outcomes among PLWHA. It is therefore essential that employment opportunities should be created for PLWHA. This is also the case in Lusikisiki where PLWHA are eager to have jobs so that the burden of living in poverty would be eliminated and their psychological well-being would be enhanced.

Govender, Fried, Birch, Chimbidi, and Cleary (2015) mentioned that social assistance in the form of a disability grant has been extended to adults living with HIV/AIDS who are unable to work as a result of chronic unemployment and deepening poverty. Some participants from Lusikisiki reported a different version to this statement as they stated that they have not received any form of assistance from the government regarding HIV/AIDS though they mentioned that disability grant payments were given to PLWHA in previous years but not anymore. These findings show that disability is complex and there is a high demand for this grant, which has brought about many challenges (Kelly, 2017). Governer et al. (2015) mentioned that PLWHA used this grant as a ticket to have an income and this led to why many PLWHA stopped taking their medications, so that they continue with their sickness, which would guarantee them getting the disability grant.

Furthermore, many people who applied for this grant did so, on false grounds whereby they received the grant on a temporary basis and when this grant elapses, they would not find employment and thus resulting in renewing their grant to maintain their income. It was further decided that the temporary grant would be discontinued when one is back to health and should be back to the labour market.

Among the fifteen participants, five of them were employed and they were comfortable as this is evident in the following responses. A calm and content employed female participant stated:

> *"I cannot say there is anything that stresses me because I am well and I do have enough to get by as I have an income and my husband is supporting my family as he is also working"* (Mrs. J., Aged 38).

With a blank face showing no emotions an employed male participant stated:

> *"I am doing well with the earnings that I get monthly and my every need is being catered for"* (Mr S., Aged 55).

Austin et al. (2017) mentioned that there is a high possibility that a PLWHA might become unemployed after one year of being diagnosed with the disease, but contrary to this statement in Lusikisiki, amongst the employed participants no one was reported to have stopped working after diagnosis. Actually, they reported having been relieved that they have jobs as they do not have the challenges of being in need because they have their income to take care of themselves.

4.3.2 Theme 2: Disclosure.

All participants have disclosed their HIV-positive status with various reasons and some participants reported to have taken some time before divulging their HIV+ status but there is one participant who has not fully disclosed the status.

This male participant with fear in his eyes and shaking his head and with his hands on his face responded:

> *"Well ...I had no option but to tell people about my status because I was very sick and the symptoms were evident"* (Mr. R., Aged 37).

An initially hesitant participant who later became bold stated:

> *"I disclosed my status with the aim of making other people aware of this disease and to encourage anyone who has it to come forward in order to get assistance because there is help available for people to manage the disease"* (Miss T., Aged 45).

A confident participant stated:

> *"I had to disclose to my family to ease the burden on me as I did not want to suffer alone…I needed support more especially emotional support"* (Mr. M., Aged 47).

A confused and sad participant stated:

> *"I eventually disclosed my status though it was quite a challenge for me to tell my ex-wife as I was afraid of how she was going to react to the news, but she eventually left me"* (Mr. C., Aged 29).

With a grin on her face the participant responded:

> *"Eeish...Though some of the people are not aware of my condition, most of them know about my HIV status, especially my friend who has given me advice in many aspects like the attire that I put on to conceal my body structure"*(Miss Z., Aged 39).

Mampa, Malema, and Lekhuleni (2015) stated that disclosure of an HIV-positive status still weighs heavily on the individuals who are faced with the obligation to disclose and even for the most self-affirming, self-confident person; it is still a difficult subject to talk about. They stated that disclosure of HIV-positive status to sexual partners, friends or relatives is useful for prevention and care as it is thought to have beneficial effects on an individual's health, lowers stress and leads to better mental health. In addition, individuals who disclose their HIV-positive status are in a better position in terms of making reproductive choices, seeking and accessing psychosocial support and facilitation of other factors, thus improving the management of HIV. Furthermore, contrary to the above-mentioned benefits, fear may hinder a PLWHA to disclose his/her HIV status, more particularly for newly diagnosed individuals who are still coming to terms with the shock of possible death.

Mampa et al. (2015) asserted that PLWHA experience conflict between the need to maintain control over personal information and the moral and ethical obligation to disclose the HIV status to people around them. Furthermore, they confirmed by indicating that disclosure of HIV status has potential risks, such as blame, divorce, abandonment, physical and emotional abuse, discrimination and stigma. In addition, circumstances and timing often vary, as some people may decide not to disclose because of concerns about potential negative consequences and some may disclose partially to specific people, while others may make a public disclosure. They mentioned that individual counseling and educational campaigns encouraging disclosure are more effective than corrective laws in preventing HIV transmission. They also mentioned that disclosure of HIV-positive status improves access to prevention and treatment programmes, including adherence to antiretroviral treatment and it can also provide increased opportunities for risk-reduction and help in planning for the future.

4.3.3 Theme 3: Healthy lifestyle.

Regarding how well they lived their life and if they were taking preventative measures to improve their health, participants reported having been trying all they could do to lead a healthy lifestyle.

After the researcher has clearly explained what the question entailed, without any hesitation the participant responded:

> *"I do use protection when having sex, which is not a problem for the father of my children as he is aware of my HIV status and is open to any negotiations regarding safer sexual activities"* (Miss N., Aged 37).

Without too much thought another participant responded:

> *"I use protection when engaging in sexual intercourse as I do talk to my partner about it but in as far as eating healthily is concerned"* in deep thoughts she further mentioned:
>
> "*Ummm...I can't say, as I do not have money to buy nutritious food since I am unemployed"* (Miss V., Aged 48).

A disappointed participant stated:

> *"At first I was not using any protection, which resulted in me being pregnant again after being diagnosed, which was irresponsible of me as I did not think of the consequences and of protecting others, but now I make sure that I use protection every time, I do try and eat healthily"* (Mrs J., Aged 39).

In doubt, the participant stated:

> *"At the moment I am abstaining from sexual activities as I have this challenge of this body shape since I do not want to be seen like this… I avoid contact with the opposite gender, but if I ever want to engage in sexual activities, I will be able to negotiate a safer sexual contact with my partner". "I eat healthily and exercise even if it is just taking a walk so that I may be healthy and continue with life regardless"* (Miss Z., Aged 39).

The participants reported having been living a healthy lifestyle by protecting themselves when engaging in sexual encounters, some of the participants though they are trying to quit taking alcohol, this has not been easy for them. They also reported that they do not go to gyms since they could not afford such things. However, they do exercise by doing their everyday chores, such as gardening and doing household chores. These findings indicated that the participant understood the meaning of healthy lifestyles by negotiating the use of condom with their partners, understanding healthy food choices, engaging in physical activities, and prevention of pregnancy behaviours including risky sexual behaviours to prevent STIs and re-infection. Moore, Jones, and Alemi (2016) established that smoking, unhealthy eating and inadequate physical activity are considered to be the behavioural risk factors, which are more prevalent in low-income and lower educational groups. In addition, environmental risk factors could also be of influence on the health of such groups as compared to those groups who have higher income and education level. Mahmaudi, Dehdari, Shojaeezadeh, and Abbasian (2015) commented that PLWHA make effort to have a healthy lifestyle by quitting smoking and drinking alcohol, having proper nutrition, physical activity and adequate sleep since that is what they view as maintaining a healthy lifestyle.

4.3.4 Theme 4: Support systems.

This theme indicated that participants had all the support they could get from different systems, such as relatives, family, and friends. Some reported having support from the community in general. Each of the participants had support one way or another.

With much assurance one participant responded:

> *"In my community, people are well-informed about HIV/AIDS so we get all the support though it is not easy financially…I do manage with the little I get from what I am doing since I am self-employed"* (Mr. D., Aged 39).

With confidence another participant stated:

> *"Since I have not quarreled with anyone regarding my illness I think I get the support I need from people around me and financially we depend only on a disability grant of one of my children and child support grant of another"* (Miss L., Aged 42).

With a heavy sigh and a feeling of sadness, one participant commented:

> *"After being diagnosed with the disease, I depended on the disability grant, which was eventually taken after a few years, but made it difficult to cope financially though we depend on the child support grant of my three children, which is quite helpful"* (Miss V., Aged 48).

These findings suggested that participants have some sort of support from family, friends and the community at large. Li, Lin, Liang, and Ji (2016) established that social support is believed to have a positive influence on PLWHA when they have to face stress related to the disease, which contributes to the treatment against HIV/AIDS and coping with aspects that are linked to the fear of death. In addition, two categories of social support had been identified, which are emotional support and instrumental support. Furthermore, emotional support is when a PLWHA feels cared for and appreciated that they are being given attention by people, as well as the availability of these important people to always assist them. While instrumental support considers the practical aspects of treatment itself in an attempt to lessen the burden on the shoulders of PLWHA, such as accompanying him/her to a healthcare centre, fetching medication for him/her or taking care of his/her children during medical visits. Li et al. (2016) also stated that social support had been considered to be essential in the prevention of diseases, promotion of health and in the process of recovering from an illness.

4.3.5 Theme 5: Empowerment programmes.

The participants mentioned support groups as the only effective programme that assists in equipping them with information and skills on how to deal with living with HIV/AIDS. Some mentioned the fact that since they are always at work they do not find time to go to these meetings, therefore, they rely mostly on information from the internet and reading materials on how to deal with challenges they face concerning the disease.

One participant stated:

> *"We, PLWHA do community mobilization teaching people on how to live a healthy lifestyle whether they are HIV-positive or not, to*

> *encourage those who are living with the disease to accept their status, adhere to treatment and be strong and carry on with life"* (Mr. B., Aged 27).

A sad and concerned participant responded:

> *"Heyyyy.....We have support group meetings where we meet to encourage and empower each other on how to live positively with HIV/AIDS. We try starting projects such as beading, gardening, and breeding chickens, but we always have a challenge with funding. No one is available to fund these projects, which will open opportunities for us as PLWHA so that we could plant our own vegetables for us to eat healthily and also do things that will generate income for us so as to eradicate poverty"* (Miss V. aged 48).

A hesitant participant commented:

> *"Ummm...Since I have not yet accepted myself completely, I still find it very challenging to go to support groups which make things very difficult for me, but I do talk with my family, friends, and cousins about the disease"* (Miss Z., Aged 39).

One participant stated:

> *"Due to the fact that I'm always at work I do not attend support groups, but I meet with my friends who attend and they share the knowledge with me"* (Mrs. J., Aged 39).

The findings show that most of the participants attend a support group because it is the only programme available for them in the community. Kalipa, Bereda-Thakathi, Tshotsho, and Goon (2014) asserted that support groups are important in the well-being of PLWHA in meeting a variety of needs, such as sense of belonging, emotional, psychological, socio-economic and health needs as well as in providing the necessary information and knowledge, because it is where support group members share relatively similar living experiences. They stated that PLWHA are able to share their emotions and problems arising from their HIV statuses, thus lessening their burdens in the process. In addition, support groups play a major role in educating people about the importance and ways of living healthily and creating a safe environment for those around them. Furthermore, they offer a helping hand to PLWHA and enable them face the world with a positive attitude, which is beneficial for their well-being. They also mentioned that PLWHA suffer a lot of complex emotional and social challenges that eventually affect their well-being. In addition, these support groups have become a key aspect of the strategies that health workers and advocacy groups offer to address the challenges faced by PLWHA. Four participants mentioned that they do miss the support group because they are always at work, however, they get information from friends when they meet.

Mundell, Visser, Makin, Forsyth, and Sikkema (2012) argued that PLWHA join support groups with the expectations of being able to trust one another, finding solutions to a universal problem, creating a sense of belonging, discussing problems and finding innovative ways of dealing with the problems, as well as learning how to comfort others with love, care, and honesty. Therefore, an understanding of these expectations is important in the success of support groups and for PLWHA to gain information that will assist them in the change in behaviour and be determined in being engaged in positive living.

4.3.6 Theme 6: Coping strategies.

In coping with stress, the participants use self-motivation, encouragement from people in general as well as spiritual coping. They also mentioned that their source of strength comes from the support groups, where they interact with people who are directly affected by the same disease as themselves.

With a smile one participant stated:

> *"Encouragement from people in general and the fact that I have a will and determination to carry on with my life despite the situation keeps me going. Fellowship with brethren at my church also gives me hope that I will be fine"* (Mr. R., Aged 37).

One stated:

> *"I have goals and vision for my future which keeps me focused and more enthusiastic to meet those goals and that keeps me going"* (Mr. C., Aged 29).

Another participant stated:

> "*Though it is quite challenging, I am trying to motivate myself so that I can eventually accept myself for who I am in spite of how I may look physically, life is too short for one to focus on regrets"* (Miss Z., Aged 39).

It is noteworthy that the community of Lusikisiki continues to encourage PLWHA. Naigino et al. (2017) argued that in some communities PLWHA are ostracised and stigmatized. Again, being strong-willed and having goals for the future is seen as a coping mechanism by one participant. This shows that self-motivation and social support play a key role in the enhancement of adherence to ART among PLWHA and strategies to build up more confidence, resilience and to facilitate self-motivation need to be put into place as coping strategies (Kim, McDonald, Kim, Foster, & Fidler, 2015). Coping as an individual is challenging as one participant alluded. She motivates herself in spite of her physical changes. Plankey et al. (2013) mentioned that these harsh body changes strongly affect the quality of life of a PLWHA and that their experience and well-being usually decrease their self-esteem and engagement in social activities. Lin et al. (2016) asserted that coping occurs when one responds to a stressful situation with social inherent methods, which are cognitive or external support systems that are behavioural. Furthermore, cognitive coping may consist of emotion-focused strategies such as acceptance of an HIV status and looking at things in a positive manner. In addition, behavioural coping includes action-oriented strategies, such as compensation through consumables, seeking support and adhering to treatment. Mahmaudi et al. (2015) mentioned that PLWHA reported coping with HIV-related stress through building a strong relationship with God and this has shown that spirituality or religion has a positive effect on PLWHA and on their well-being and quality of their life. In addition, not much attention has been given to this strategy by professionals, which is why it is important that health professionals and psychologists seek ways to assist PLWHA to meet their religious and spiritual needs. Furthermore, another coping strategy used by PLWHA is called 'intellectualization' whereby one overlooks his/her uncomfortable emotions and focuses his/her mind on facts and reason. Mahmaudi et al. (2015) also stated that support from peers is another strategy that was reported by PLWHA to be helpful, as lack of support may affect coping efforts with physical health outcomes of PLWHA in a negative way. They stated that social groups could assist PLWHA not to be alone as they are provided with all the support and advice they could get.

4.3.7 Theme 7: Self-acceptance.

For the theme of self-acceptance, most of the participants had been diagnosed with the disease and had been on ART for a long time. Majority of them had been diagnosed for over five to fifteen years, while there were a few who were diagnosed for two to four years. However, except for one participant, the remaining of them reported to have accepted themselves.

One participant stated:

> *"It's been three years now since I was diagnosed with HIV and I have been on treatment for two". "I have accepted my HIV-positive status because I realized that is the only thing I could do in order for me to carry on with my life"* (Mr. C., Aged 29).

With a sigh of relief another participant responded:

> "*I was diagnosed in 2004 but I had to first take TB treatment before being given ARVs, then I started ART in 2005. At first, I was shocked to find out that I was HIV-positive, but then having known how reckless I lived my life, I came to accept my status which made me strong and be ready to face whatever challenge that would come my way. Accepting myself made me to be content and to be at peace with who I am regardless of what others think of me"* (Miss V., Aged 48).

Sounding so hurt and sad one participant mentioned:

> *"It's been eight years since my diagnosis and I've been on treatment for three years". "I have accepted my status, but have not accepted the*

way the disease has drastically changed the shape of my body" (Miss Z., Aged 39).

These findings indicated that most participants have accepted their HIV-positive status as fourteen of them eluded. Horter et al. (2017) mentioned that HIV status acceptance is important for a person's engagement with HIV care and access to social support, quality counseling, knowledge, attitudes and practices regarding health care. In addition, the process of status acceptance is influenced by an individual's awareness that there is a heightened probability that they would receive a HIV-positive result. Furthermore, while the exact way in which one processes a HIV-positive result is diverse and individually defined, certain factors could influence the transition towards acceptance. They stated that these factors include the perception of the risk for potential HIV infection including judgments about HIV, an association of self with images of HIV positivity, counselor support offering reassurance, encouragement, and hope for life after diagnosis. They also mentioned that non-acceptance of HIV-positive status often termed as denial, can negatively affect individual's access to HIV care, ART initiation and adherence and this denial had been linked with poor mental and physical health. They claimed that time can be required in order for one to come to terms and accept a HIV-positive status.

Rohleder et al. (2017) stated that significant advances in medical treatment in HIV means that it is no longer a death sentence but can be regarded as a chronic, manageable illness. Factors that predict a worsening in physical health were found to include financial constraints, body disfigurement and these reflect the importance of social policies implemented to ensure that basic economic conditions required by these people are covered, and the important role played by social workers when it comes to facilitating access to social resources and programs. Furthermore, the importance of working with patients in psychological intervention programs on body acceptance due to lipodystrophies needs to be highlighted.

4.3.8 Theme 8: Personal growth.

Despite the fact that people are living with HIV/AIDS, they still see the future and have plans for it as they still have hope to carry on with their lives, while some hoped to get the courage to accept circumstances in their lives.

After thinking for a moment one participant stated:

> *“Nothing has changed in as far as my future goals are concerned, as I am still looking forward to reaching the goals I have set for myself”* (Mr. C., Aged 29).

Another mentioned:

> *“As I am not working, I will carry on looking for a job as it is my wish to be able to take care of myself and becoming someone in the future”*(Mr. B., Aged 27).

Another stated:

> *“My wish is to keep on living my life positively while carrying on to take care of my family as a husband and a father”* (Mr. S., Aged 55).

Seeming determined one participant responded:

> *“In order for me to grow, I am building towards having the courage to stop using this attire I am using to cover myself. I want to accept the way I am and carry on with my life without any limitations”* (Miss Z. aged 39).

These findings suggested that participants are focusing on their personal growth, as well as future goals and self-development. Overbaugh, Parshall, and Faan (2017) established that personal growth has been defined as one’s capability to identify positive changes in one’s priorities, personal relationships and values when facing difficulties. This is referred to as post-traumatic growth in individuals who are living with life-changing illnesses. In addition, in PLWHA higher levels of personal growth is linked with positive outcomes including better adherence with ART. Furthermore, personal growth is characterized by some degree of change in one’s personality that develops when one is trying to come to terms with a medical diagnosis that interrupts one’s life, which regularly entails some transformation in one’s beliefs of how he/she looks at the world and his/her responsibility in it.

Rodkjaer et al. (2017) maintained that in order for PLWHA to grow, they had to integrate a mindset which would allow them to be resilient over a period of time as they gain insight on how they react and find new ways and improved skills to act in a more positive, healthy and balanced manner, despite the physical and psychological transformation that crops up with HIV diagnosis. In addition, it is of vital importance that PLWHA be given liberty to do what they decide to do at their own pace on how they intend living their lives.

4.3.9 Theme 9: Autonomy.

Participants are aware that they still have something to live for as they showed self-determination and were able to make their own decisions without any influence. One participant stated:

With a smile in her face the participant stated:

> *"Ummm...My dream is to own my own business whether it is selling chickens and beads, although the challenge is capital to start"* (Miss V., Aged 48).

Hesitating for a moment another participant responded:

> *"I can't say that I eat healthily as I eat whatever is available as I do not have money to buy that nutritious food, I never took alcohol even before being diagnosed with HIV/AIDS and I use condoms when involved in sexual intercourse as I am able to negotiate the issue with my partner"* (Miss L., Aged 42).

After a moment the participant responded:

> *"During the week I am not able to attend support group meetings as I'm always at work, but I do attend during holidays when I get the time. I do equip myself by using the internet and books, for any information that I require to know more about the disease and to know about the current situation about the disease"* (Mr. R., Aged 37).

These findings suggested that the participants still have dreams for their lives and they are able to make decisions about their lives regardless of how other people feel. This means that they are capable of taking initiative without considering other people's opinion about their lives. Atteraya et al. (2014) argued that women who score high in autonomy are well-informed on HIV-related issues and condom use and have the ability to negotiate safer sexual encounters with their partners. Sano, Sedziafa, Vercillo, Antabe, and Luginaah (2018) characterized women's autonomy as women's ability to make decisions and be in control of matters concerning their bodies. In addition, economic empowerment has a major impact on women's decision making autonomy, which will then lead to their ability to ask for safer sex with their partners. It is therefore important that the environments which increase women autonomy be promoted. Seymour and Peterman (2018) asserted that autonomy emphasizes one's ability to act on behalf and according to his/her own personal values.

4.3.10 Theme 10: Purpose in life.

The participants had a brighter future in their minds as they are still looking forward to what tomorrow holds for them.

Looking very excited one participant commented:

> *"I want to carry on with my life, carry on with acquiring more knowledge in relevance with the kind of work I am doing, as I have been doing and making a better future for my family"* (Mrs. J., Aged 38).

With so much enthusiasm the participant mentioned:

> *"My wish is to get well and be able to gain my strength back and be able to plant vegetables in my garden so as to have something to live by and be able to take care of my children."* (Miss L., Aged 42).

These findings suggested that participants had a will and zeal to live and do better in life regardless of the circumstances they found themselves. They were eager to rise up and carry on with their purpose in life. Vijayakumar and Vijayabanu (2014) mentioned that a positive attitude can have a tremendous impact on one's life and if one approaches any traumatic life event with a positive attitude, one would be able to move forward constructively and fulfill his/her purpose in life. Fekete, Chatterton, Skinta, and Williams (2016) commented that benefit finding is one factor that is linked to better adjustment in PLWHA, meaning that it is an individual's perception that he/she has experienced change as a result of a traumatic event and therefore, life needs to go on. Lee, Nezu, and Nezu (2014) argued that when faced with challenges, people put more effort into understanding the impact and significance that specific life circumstance has in one personally by perceiving its meaning. In addition, through the search of that meaning one may identify a positive view from that stressful situation and find benefits from it.

4.3.11 Theme 11: Environmental mastery.

The participants tried all means, to adjust to their present situation by changing their attitude and mindset towards the disease.

Looking determined, one participant stated:

> *"Ooo...ja...Having accepted my present situation I am strong-willed and determined to work towards achieving my goals, while showing the young people that there is life after HIV if one puts his/her mind to it"* (Miss T., Aged 45).

Nodding gently one participant commented:

> *"Jaaa.....It's been eleven years since I was diagnosed with HIV infection and I have accepted that this has happened to me to make me strong and that has made me realize that there is nothing that may hinder me in becoming what I am destined to be. I did introspection and convinced myself that I need to live and carry on with life as everything starts with the mind"* (Mr. S., Aged 55).

With confidence, the other participant responded:

> *"We do appreciate the efforts made by the government in providing us with treatment and health care services and we have also adapted well*

> *even in our communities, but there is a need for the government to do a follow-up and investigate on how we are coping after treatment and to find out whether people have nutritious food to take with treatment"* (Miss V., Aged 48).

These findings suggested that participants have adjusted well in their environments and are taking full advantage of resources available, such as health care centres and the services rendered. Fave (2017) commented that environmental mastery is a key moderator of stressful experiences. He further mentioned that an individual has the ability to solve his/her problems, rather than being overcome by external forces, but can also make time to rest and relax in daily life. In addition, Fave (2017) came up with an example that, an individual might arrange training sessions, travel to the gym and exercise in a normal surrounding as a normal person, rather than a PLWHA which would boast one's confidence.

4.3.12 Theme 12: Positive relations.

The participants had built trust and satisfying relationships with each other and those around them because they believe they are in the same situation together.

Thinking for a moment the participant stated:

> *"Though I have no children of my own, I do have the responsibility to my siblings whom I love so much, which is why I have dreams that may I live longer so as to take care of them and we live as a big happy family"* (Mrs. S., Aged 45).

One participant stated:

> *"It's been four years since I've been living with HIV and I have accepted my fate, I make it my responsibility that I build healthy relationships around me and I am so encouraged by the fact that people around me have accepted me"* (Mr. B., Aged 27).

With a smile on her face, the participant commented:

> *"Prayers, advice, and encouragement from people, in general are key elements to my well-being, I have built myself a new home and family among the brethren"* (Mrs. J., Aged 39).

Feeling emotional the participant stated:

> *"The fact that I have people who still love and value me for who I am, gives me reason enough for me to hold on"*(Mr. C., Aged 29).

These findings suggested that participants have built strong relationships amongst themselves, their families and the community at large including churches and health care workers. They interact well with other people. Russell et al. (2016) established that positive relationships with health care workers are of importance for PLWHA more especially in the first month after one has bee diagnosed with the disease and commenced with treatment. Rohleder et al. (2017) commented that good social relationships in PLWHA improve their well-being and enhance their psychological coping in times of stress.

4.4 CONCLUSION

In the previous chapter, the information that was collected through interviews was scrutinized in order to have a meaning of the world through the eyes of PLWHA on how they live and they cope while living with the disease and how they deal with the challenges they come across along their journey to recovery. The researcher will present the summary of findings, limitations, and recommendations in the next chapter.

CHAPTER 5: SUMMARY OF FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This is the last chapter on the exploration of the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape, South Africa. It summarizes the work of the whole dissertation through the use of interviews and the period of data collection. This chapter also includes the major findings, limitations and the recommendations.

5.2 SUMMARY

The objectives of the study were to:

- Explore the factors that influence the psychological well-being of PLWHA in Lusikisiki.
- To describe the strategies PLWHA use to deal with the consequences of stress in Lusikisiki.

A qualitative exploratory design was employed for this study. The researcher conducted semi-structured interviews for data collection with a purposive sample of fifteen PLWHA that belonged to one of the support groups under the supervision of the Treatment Action Campaign (TAC) District office in Lusikisiki. The interview schedule used for the study had two sections. The first section contained details on the bibliographical information of the participants and the other section contained open-ended questions.

5.3 MAIN FINDINGS

5.3.1 Demographic information.

From the fifteen participants involved in the study, seven were males and eight were females. However, within the age brackets of the participants involved in this study, two of the participants range between 20 and 30 years, six of them were in the cohort of 31 to 40 years, five participants were from 41 to 50 years age cohort and two were between the cohort of 50 to 60 years. Out of the fifteen participants, nine were single, three were married, two were widowed and one divorced. All the participants had some form of formal education as two had primary education, nine had secondary education and four had tertiary education. In addition to their employment status, eight participants were unemployed, two were self-employed and five were employed. However, seven of the fifteen participants do receive an income of R1500 monthly, four of them do receive between R1500 to R3500 monthly income while another four receive over R3500 monthly income.

5.3.2 Themes.

Various themes were identified in the study, which are unemployment, disclosure, healthy lifestyle, support systems, empowerment programmes, coping strategies, self-acceptance, and personal growth. Also, from the findings, there are various factors that influence the psychological well-being of PLWHA in Lusikisiki, which are either in a positive or negative manner. Among these factors is unemployment, which has a negative impact on the lives of PLWHA in Lusikisiki. It was therefore established that, most participants struggle to make ends meet because of low socio-economic status as a result of not being employed. It was also reported that PLWHA solely depended on child support grants for survival, which puts more strain on the quality of their lives, as a result of a constant worry on how to make provision for themselves and their families. This compromises their state of psychological well-being. Gebremichael et al. (2018) however, mentioned that it is vital that employment opportunities be created for PLWHA.

Nevertheless, employed PLWHA reported being well and able to survive, but they as well stated the few challenges though they do not lack basic needs. In contrary to this Gebremichael et al. (2018) asserted that the risk of being unemployed is very high within one year of being infected with HIV. PLWHA reported that being employed had made things easier for them and that they have something to look forward to every day. All the participants reported having disclosed and accepted their HIV-positive status due to various reasons, some disclosed so that they can get support from loved ones, in order to ease the burden from their shoulders, while some were forced by circumstances to disclose and they accepted their status so as to carry on with their lives. There was, however, one participant who reported to have disclosed and accepted her HIV-positive status, but yet to accept the way her body has changed drastically due to the side effects of the medication. The participants reported trying to live healthily by protecting themselves when having sex, by abstaining, exercising and eating healthily. Some of them reported that they were trying to stop taking alcohol though they were still encountering challenges in doing so. All the participants were getting support in one way or the other, especially emotional support from friends, relatives, family and the community in general.

The participants reported having only support groups as an empowerment programme where they empower and encourage each other by sharing their experiences with each other. They also reported that they used self-motivation and spirituality as their coping strategies when dealing with stress and its consequences, which enhance their psychological well-being, thus enabling them to live a prolonged and stress-free life. In agreement with this statement, Probst et al. (2016) commented that modified coping skills, which include positive appraisal and spiritual methods promote psychological relief in PLWHA.

5.4 LIMITATIONS

The participants could not clearly get the meaning to some of the questions and this allows for the constant repeating of questions by the researcher during the interviews. Besides, PLWHA were not that keen participating in the study because they complained that so many studies had been conducted by various institutions, but no change had been brought to their communities. They however, asked the researcher what the main purpose of research was and whether it will be of benefit and bring change to their lives. Furthermore they were of the opinion that there should be a benefit for them participating in the study, which will address their issue of starvation.

5.5 RECOMMENDATIONS

Having looked at the experiences of PLWHA, various recommendations were formulated based on the findings of the study.

5.5.1 Assistance by the government.

It is recommended that there is a need for the government to provide some form of assistance whether as food supplement grant or some food parcels for those living with HIV/AIDS and struggling with food insecurity so that their treatment may be able to be effective. PLWHA reported that in earlier years, disability grant was given to those who were on treatment, but was stopped due to various challenges surrounding it.

5.5.2 Community projects

It was also recommended that a much sustainable option would be to establish community projects, such as gardening where vegetables would be planted, breeding chickens and beading. People who have capital like businessmen and government should provide funding for such projects as financial constraints are a major obstacle in starting these projects. These finances also need to be monitored very closely to see that they are doing what they are supposed to be doing. This would assist PLWHA to be able to have some income for themselves and also to have something nutritious to take with antiretrovirals. These projects would open job opportunities for unemployed PLWHA, which would keep them busy and that would enhance their quality of life while bringing back their dignity as human beings and improved psychological well-being.

5.5.3 Ways of making recommendations be of benefit to communities

Researchers need to take a step further after conducting the study with the communities. They need to come up with ways to expose their findings such as publishing journal articles, presenting at conferences, making copies of dissertation to be available in libraries and online so that they could be of access to the relevant people such as policy makers and funders so that they can be of benefit to communities. This would also show the communities that researchers are not conducting studies just for the sake of doing so, but they could see that they are of much benefit to the communities, which would encourage them to participate in future studies having seen that there is a change in their communities as a result of research.

5.6 CONCLUSION

The aim of the study was to investigate the psychological well-being of PLWHA in Lusikisiki, in the Eastern Cape. The study employed a qualitative exploratory design where the researcher conducted semi-structured interviews on fifteen PLWHA. Much effort had been done to curb HIV/AIDS through the implementation of preventative measures and the provision of treatment to manage the disease but not much has been done to monitor and to do the follow-up on how PLWHA are surviving and coping psychologically, socially and physically on their daily lives. Based on the findings, the psychological well-being of PLWHA in Lusikisiki is influenced by many factors of which some have a negative and some have a positive impact. Factors, such as self-acceptance, disclosure, healthy lifestyle and support systems have positively influenced and improved the quality of life of PLWHA in Lusikisiki. However, there are those factors that have a negative impact on the psychological well-being of PLWHA in Lusikisiki including unemployment. In the findings, it was also reported that PLWHA use coping strategies such as self-motivation and spirituality to deal with the stress of their everyday lives of living with the disease.

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APPENDIX A

University of Fort Hare
Together in Excellence

Name of town: Lusikisiki

Section A: demographic information

Instructions: answer all questions and mark with an 'X' where appropriate.

1. Gender

   a) Male { } b) Female { }

2. Age(years)

20-30	31-40	41-50	51-60

3. Marital status

Single { } Married { } Widowed { } Divorced { } Other { }

4. Highest Education

Primary education	Secondary education	Tertiary education	No education

Primary education	Secondary education	Tertiary education	No education

5. Source of income

Self-employed	Employed	Pensioner	Other (specify)	

6. Income levels

Income level	Please tick
Under R1500 per month	
Over R1500 to R3500 per month	
Over R3500 per month	

7. Religion

Christianity	Traditional healing	Combination of both	Other (specify	

8. <u>Number of children</u>

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<u>Section B:</u>

1. Unexesha elingakanani uphila nentsholongwane kagawulayo?

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2. Ingaba sele uyamkele into yokokuba uphila nentsholongwane kagawulayo? Ewe okanye hayi ubeke nesizathu.

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3. Ingaba sele uzazisile izizalwane nabahlobo bakho ngalemeko ukuyo? Beka nezizathu zokuba ubazise okanye ungabazisi ngale meko.

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4. Uwatya ngokwemiyalelo yawo nangokufanelekileyo amachiza entsholongwane kagawulayo?

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5. Unalo ulawulo lesiqu sakho, njengokuphila ubomi obamnkelekileyo, utye ukutya okulungileyo nokuya egazini nokuzilolonga?

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6. Ziziphi izinto ezakhayo nezikhulisayo nina bantu baphila nalentsholongwane kagawulayo enizenzayo ekuhlaleni ukuphuhlisa amakhono enu nokuphakamisana?

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7. Emveni kokufumanisa ukuba uphila nentsholongwane ingabe uthini umbono wakho ngobomi bakho ukususela ngoku ukuya kwiminyaka ezayo? Njengo kuya esikoloweni njalo-njalo.

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8. Kubantu abakungqongileyo nophila nabo uyakufumana ukwesekelwa kangangoko unqwenela? Basakuphathanjengakuqalanobangokwahlukileyokunakuqala?

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9. Ngokwasezimalini uyayifumana inkxaso? Ukuba ewe ngubani okuxhasayo ukuba hayi uphila njani?

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10. Ekuhlaleni njengokubanzi ingaba inkxaso iyafumaneka, bakuphatha njani abantu nje abakungqongileyo?

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11. Ingaba ikho enye into onqwenela ukuyivelela esingakhange siyichaphazele apha ngasentla?

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UMBULELO OMKHULU NGENTSEBENZISWANO!!!

APPENDIX B

University of Fort Hare
Private Bag X1314
Alice
5700
30 October 2017

Treatment Action Campaign (TAC)
Embassy Building
Jacaranda Street
LUSIKISIKI
4820

Dear Sir/Madam

Re: request for permission to conduct a study on the psychological well-being of People Living with HIV/AIDS (PLWHA).

I am Nombulelo Nodwengu (student number 201102962), a masters student in the Psychology Department from the above mentioned University. I kindly ask you to allow me to conduct my research study entitled “The exploration of the psychological well-being of People Living with HIV/AIDS in Lusikisiki, in the Eastern Cape”. The aim of the study is to explore the factors that influence their psychological well-being.

The interview schedules will be distributed and interviews conducted by the researcher to PLWHA who come to your office. The study in question will guarantee each and every participant informed consent, confidentiality, protection from harm and honesty from the researcher.
The permission for this research had been obtained from the Ethical Committee of the University of Fort Hare in Alice before the research is conducted.

My supervisor is Mrs. V. N. Hoho and for more information please contact her on these contact details, 082 399 5008 or email her onvhoho@ufh.ac.za.

Thanking you in advance

N. Nodwengu
078 2460019/ 073 4204706
E-mail: 201102962@ufh.ac.za

APPENDIX C

University of Fort Hare
Private Bag X1314
Alice
5700

To whom it may concern

Dear respondent

I am a student from the Department of Psychology at the University of Fort Hare, conducting research on “The exploration of the psychological well-being of People Living with HIV/AIDS in Lusikisiki”. The research is for academic purposes and ethical issues such as informed consent, confidentiality and anonymity shall be observed at all times. This then will ensure that no harm comes to any of the participants as a result of the research. For me to successfully graduate I need to conduct a research on some of the social phenomena in existence.

The latter will require interviews and interview schedules to be distributed amongst Lusikisiki community, specifically at the Treatment Action Campaign (TAC) office. I then humbly request permission to interact with the Lusikisiki community, for the completion of the research. I am here binding myself to the notion that all information derived from participants will remain confidential. All participants will not be coerced, as this is a voluntary process. None of the participants will be compensated, as this is non-funded study.

For any further enquiries, please contact me through the following contact details:

Name of student	Name of supervisor
N. Nodwengu	Mrs. N.V. Hoho
078 2460019 082 3995008	
201102962@ufh.ac.za	vhoho@ufh.ac.za

APPENDIX D

INFORMED CONSENT

I hereby agree to participate in research regarding **the exploration of the psychological well-being of People Living with HIV/AIDS in Lusikisiki, in the Eastern Cape, South Africa.** I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential.

I understand that if at all possible, feedback will be given to my community on the results of the completed research.

……………………………..
Signature of participant **Date**:…………………..

I hereby agree to the tape recording of my participation in the study

APPENDIX E

University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE
REC-270710-028-RA Level 01

Certificate Reference Number: HOH011SNON01

Project title: **The exploration of psychological well-being of people living with HIV/AIDS in Lusikisiki in the Eastern Cape.**

Nature of Project: Masters in Psychology

Principal Researcher: Nombulelo Nodwengu

Supervisor: Ms V.N Hoho
Co-supervisor: N/A

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

Special conditions: Research that includes children as per the official regulations of the act must take the following into account:

Note: The UREC is aware of the provisions of s71 of the National Health Act 61 of 2003 and that matters pertaining to obtaining the Minister's consent are under discussion and remain unresolved. Nonetheless, as was decided at a meeting between the National Health Research Ethics Committee and stakeholders on 6 June 2013, university ethics committees may continue to grant ethical clearance for research involving children without the Minister's consent, provided that the prescripts of the previous rules have been met. This certificate is granted in terms of this agreement.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
    - Any unethical principal or practices are revealed or suspected
    - Relevant information has been withheld or misrepresented
    - Regulatory changes of whatsoever nature so require
    - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.
- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely

Professor Lindelwa Majova-Songca
Acting Dean of Research

10 November 2017