A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa

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I Relebohile Lerato Tsotetsi hereby declare that the work contained in this dissertation is my own and all sources I have drawn on have been acknowledged by means of complete references.

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Relebohile Lerato Tsotetsi

Date: 31 October 2017
REMARKS

The reader is kindly requested to take note that this mini-dissertation has been written in the NWU approved article format, which consists of an introductory chapter, one research article containing the main findings of the study, and a final chapter outlining the conclusions, limitations, and recommendations pertaining to the study.
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ABSTRACT

**Topic**: A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa.

**Key terms**: Flourishing, HIV/AIDS, South Africa, well-being

This mini-dissertation presents the findings of a study that qualitatively explored flourishing among individuals diagnosed with HIV/AIDS in South Africa. A purposive extreme case sampling method was used to obtain 15 participants (7 male, 8 female) who were identified as flourishing via a combination of their CD4 counts and reports from their supervising physicians. All participants were from communities near Heilbron in the Free State province of South Africa, and made use of Tokollo Hospital as their health care facility. Data were collected by means of semi-structured interviews. Most interviews took place at the participants’ homes and a few took place at Tokollo district hospital over a three-month period from February 2017 to end of April 2017. Data were analysed by means of thematic content analysis. Eight main themes emerged from the data, which served to account for how individuals diagnosed with HIV/AIDS in South Africa are flourishing despite their diagnosis. In particular, acceptance of their diagnosis; having a positive outlook on life; taking responsibility for their condition; drawing strength from faith and religious activities; having supportive social relationships; having a future orientation; motivating and encouraging others with the same illness; and music were identified as those factors that contribute to flourishing among the participants. Furthermore, participants commonly mentioned that by accepting their diagnosis, they were able to take responsibility for their lives and choose to adopt a positive and healthy lifestyle for themselves, which involved eating a healthy diet, exercising regularly, and adhering to their medication regimens. Furthermore, these participants pointed out that their faith and religious practices keeps them hopeful and also optimistic for a better future. Also, they indicated that they did not perceive their diagnosis as all negative, because it allows them to motivate and serve as example to others who are facing the same challenges in life and who are not coping with their diagnosis. Most participants also noted that getting support from primary relationships such as family and friends also gives them more reason to continue on a positive journey and not be influenced by negativity from stereotypes, stigma and discrimination often associated with the disease. The mini-dissertation is concluded with a chapter outlining the conclusions, limitation, implications and recommendations as well as obstacles encountered during the course of the
study. With this intention, it is also the researcher’s recommendation that more research be conducted to explore flourishing among a more diverse sample of HIV positive individuals. It is also recommended that the findings of the study be considered when developing interventions or providing training for HIV counsellors in order to assist patients that are languishing as a result of their diagnosis.
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CHAPTER 1
INTRODUCTION, PROBLEM STATEMENT AND OBJECTIVES

1.1 Introduction

This study aims to qualitatively explore flourishing among individuals who are diagnosed with HIV/AIDS in South Africa. As such, this chapter comprises a detailed step-by-step outline of the study and how the research was executed. Firstly, a literature review is provided, which will provide an overview of existing research related to the topic, and which will also clarify important terms and concepts relevant to the study. The literature review will be followed by an outline of the research questions and aims that guide the study. The theoretical framework that has been chosen to frame the study will then be discussed. The research methodology applicable to the study will be elucidated next. The methodology will comprise the research design, sampling procedures, data gathering methods as well as an outline of the method of data analysis applicable to the study. Trustworthiness and quality assurance of the study will be explained next, followed by a discussion of the ethical issues that are relevant to the present study. This chapter will then be concluded by an outline of the chapters of the mini-dissertation.

1.2 The HIV/AIDS pandemic

The Human Immunodeficiency Virus (HIV) has changed lives immensely across the world over the past 30 years (Hessol et al., 2007:1144). The virus broke out on a significant scale in 1981 when the United States of America officially recognized an uncommon illness among a small group of gay men. The disease affects all ages, sexes and races due to multiple transmission factors. HIV is passed from one person to another by means of blood-to-blood or sexual contact. The virus depletes the functioning of the T-helper lymphocytes also known as the CD4 cells (ILO, 2014:3). The CD4 cells are the major target of viral infections and they circulate within the blood. An untreated person would experience weakening of cells (Hessol et al., 2007:1144; ILO, 2014:3). In the case of loss of an effective immune response to the allocated opportunistic pathogens, the HIV infection progresses into Acquired Immune Deficiency Syndrome (AIDS), which is of great concern, as it is widely spread across the world, and is a disease of great demographic diversity (Hessol et al., 2007:1152).
The pandemic continues to spread around the world without full control in any country (Lawson et al., 2006:4). The disease is estimated to have infected over 58 million people worldwide and is rated as the fourth leading cause of mortality globally. An alarming 95% of people infected in the world are said to be in sub-Saharan Africa. The AIDS epidemic is said to have caused more fatalities than malaria in Africa (Lawson et al., 2006:4). The pandemic is not only a heavy burden for people who have the disease but it also affects families as many children are left orphaned. Complicating matters further is that HIV/AIDS is often accompanied by other sexually transmitted diseases, which are said to hinder the control of HIV itself (Lawson et al., 2006:4).

South Africa is known as one of the leading countries in HIV/AIDS research in relation to the treatment and the prevention of the disease (Shisana et al., 2014:3). The comprehensive and long-term research in this country has produced significant amounts of statistical data on the prevalence and incidence of HIV/AIDS, and also on anti-retroviral treatment (ART). Conjointly, there has also been a rising awareness with regards to socio-behavioural and structural conditions that contribute to the spread of HIV infections in the population (Shisana et al., 2014:3; Stats SA, 2014:6). An overall percentage of 16.9% of children between the ages of 0-18 years have been orphaned in South Africa with 18.9% of the children being from black African communities. As a result of socio-behavioural risks, the young women in South Africa prove to be at risk of HIV infections because of age-disparate relationships they enter into (Shisana et al., 2014:4). Likewise unmarried persons are said to be at higher risk than married people because of higher percentages of unmarried people with multiple partners (Shisana et al., 2014:4).

Statistics South Africa reported an overall estimate of 10.2% HIV prevalence in the South African population in the year 2014 (Stats SA, 2014:2). The estimated number of people living with HIV in South Africa in 2014 was approximately 5.51 million, with adults aged 15-49 years estimated to make up 16.8% of the population. Reports have shown a decline in AIDS deaths compared to 2005 figures, which is mainly attributed to the increase and distribution of antiretroviral treatment “ART” (Shisana et al., 2009:63). The South African government, supported by international partnerships and civil society mobilisation, are investing ever more in evidence-based treatment and preventative strategies in response to the epidemic.
1.3 HIV/AIDS and stigma

Societies across the globe encounter an array of negative and inaccurate ideas spread about HIV/AIDS (Shisana et al., 2009:71), which commonly brings into existence stigma and discrimination (Meiberg et al., 2008:50). Stigma refers to disapproving feelings people have about a particular illness and ways of behaving (Lawson et al., 2006:8). Individuals who are stigmatised are either blamed or marked as being different from other people (Lawson et al., 2006:4). Such people can even be insulted, rejected, gossiped about and also excluded from social activities (Meiberg et al., 2008:50). Discrimination on the other hand is defined as the practice of treating somebody, or a particular group in society less fairly than others. The act of discrimination commonly denies people the right to vital information and/or services that protect them against HIV infection, as well as the receiving of appropriate treatment, care and support (Meiberg et al., 2008:50).

In South Africa, HIV positive individuals still encounter psychosocial factors such as denial, stigma, and lack of support and resources, which has been found to be significantly associated with the onset of mental health problems such as depression (Anderson & Seedat, 2009:12). Furthermore, individuals diagnosed with HIV/AIDS not only encounter difficulties with the virus, and with attendant mental health challenges, but also often face discrimination from their partners and the family members they live with. The stigma of HIV/AIDS then leads to loss of social support and isolation (Louwrens, 2014:4). The discrediting of an HIV-positive person or group often results in a situation where such individuals are denied services important to their lives, and where their human rights are violated (Stangl et al., 2013:1; Katz et al., 2013:1).

1.4 Problem statement

Numerous studies have been conducted globally on the HIV/AIDS pandemic, and most of these studies tend to focus on the negative outcomes associated with HIV/AIDS such as stigma (Lawson et al., 2006; Meiberg et al., 2008). Promotion and prevention strategies have also been a primary focus in the context of the research that has been conducted (WHO, 2002:2; UNAIDS, 2010:5; Coates et al., 2008:671). As a result of the vast research, the World Health Organisation (WHO) published a guide to nutritional care and support for people living with HIV/AIDS (WHO, 2002:2). Other crucial research includes looking at individuals receiving antiretroviral therapy and having difficulties sticking to their current
programme, their satisfaction with social support, coping styles and punishment beliefs about HIV/AIDS (Safren et al., 2002:478; UNAIDS, 2000:5; Kotzé, 2011:24; Haruna & Ago, 2014:78). As such, the emphasis of much existing research has been on the challenges associated with HIV/AIDS and on the treatment and prevention of the disease. As such, although voluminous research has been conducted on HIV/AIDS, comparatively not much research has specifically focused on well-being and flourishing among people living with HIV/AIDS.

As conceptualized in this study, flourishing refers not just to the absence of symptoms of ill mental health and illness, but to the prominence of mental health symptoms (Baumgardner & Crothers, 2007:270). Flourishing is comprised of two components, namely hedonia (‘feeling good’), and eudaimonia (‘functioning well’) (Wissing et al., 2014:8). The feeling good dimension involves that an individual is satisfied with his or her life and experiences more positive than negative emotions. The second dimension of ‘functioning well’ entails that the individual experiences meaning in his or her life, has harmonious relationships with others, is self-determined, has good social relations and is optimistic (Wissing et al., 2014:255). The experience of autonomy, experiencing satisfaction with life, having hope and resilience and having purpose and finding meaning in life are basic factors that lead to flourishing (Wissing et al., 2014:225). To be diagnosed as flourishing, therefore, an individual should exhibit convincing amounts of both eudaimonia and hedonia (Keyes, 2007:98).

At the opposite end of the continuum from flourishing there is languishing, which is a state in which an individual lacks positive emotions towards life. Such a person is not functioning well psychologically or socially and has been depressed recently (Van Schalkwyk, 2009:10). People who have been diagnosed with HIV/AIDS are more likely than those not diagnosed as such to develop mental health problems like depression and anxiety (NAT, 2010:3).

A review of existing literature reveals that a comparatively limited number of international studies have been conducted on well-being and HIV, with a number of them focussing on factors such as psychological well-being and the impact of social support for diagnosed individuals. One study on flourishing HIV individuals was conducted on HIV-positive Australian gay men, and in it the researchers found that the gay men generally flourished despite their diagnosis, though they concluded that there is still a need for resilience programs to help diagnosed individuals in the future (Lyons et al., 2016:3). Another study explored HIV self-management and well-being among people taking antiretroviral therapy in Uganda.
(Russell et al., 2016:92). The particular study found that individuals were managing their condition well in psychological, social and emotional well-being (Russell et al., 2016:92). Despite these studies, comparatively little research has thus far been conducted on flourishing amongst individuals diagnosed with HIV/AIDS, especially in South Africa (Van Schalkwyk, 2009:6). A review of journals published and not published via databases such as Ebscohost, Google Scholar and other sources were consulted but virtually no research could be located that expressly focused on flourishing amongst individuals diagnosed with HIV in South Africa, which represents a significant gap given the unique and diverse cultural profile of this country. Given that values, beliefs and norms pertaining to illness and illness behaviour commonly vary across cultures (Cockerham, 2001:158), findings from previous studies done in other contexts cannot be indiscriminately generalised to the South African context, and a need exists for contextually sensitive investigation of the topic. Acquiring some understanding on how individuals diagnosed with HIV/AIDS are flourishing could yield many benefits. Firstly, the findings from a study such as this might be fruitfully employed to inform and guide the development of strategies and interventions aimed at helping those who seem to not flourish after they are diagnosed with HIV/AIDS. Secondly, this will allow for a better understanding of how such individuals are able to flourish in spite of stigma and discrimination. Such information might be useful to therapists and counsellors working with individuals who have contracted HIV/AIDS. These include lay counsellors who provide pre-diagnosis counselling for individuals, counsellors and psychologists who have to provide therapy for HIV-positive patients, as well as nurses and doctors working with individuals diagnosed with this condition.

1.5 Research questions

1.5.1 Main research question

Based on the discussion in the previous section, the following main research question was formulated to guide the present study:

How are some individuals diagnosed with HIV/AIDS flourishing?
1.5.2 Secondary research question

What are the factors that contribute to flourishing amongst individuals diagnosed with HIV/AIDS?

1.6 Research aims
1.6.1 Main research aim

The general aim of this study is to qualitatively explore flourishing amongst individuals diagnosed with HIV/AIDS.

1.6.2 Secondary research aim

To explore the factors that contribute to flourishing amongst individuals diagnosed with HIV/AIDS.

1.7 Methodology

1.7.1 Literature review

The literature review for this study entailed reading and analysing the available scholarly writings on the research topic, which guided the overall direction of this research process (Hofstee, 2006:91). The available literature was sought through official publications, dissertations, published theses, newspaper articles, newsletters, general web pages, reviewed journal articles and other informal reports, as recommended by Krueger (2012:9). These were sought on databases such as Ebscohost, Sabinet, and Google Scholar, library books, JSTOR and more. To guide the search the following key words were used: flourishing, HIV/AIDS, well-being, psychological well-being, eudaimonia, hedonia, meaning in life, after-diagnosis, resilience, etc.

1.7.2 Empirical Study

The current study aims to explore flourishing amongst participants diagnosed with HIV/AIDS. This is best accomplished by studying the participant’s personal knowledge and understanding of themselves. A qualitative approach will therefore be adopted for the study.
A qualitative approach is concerned with achieving in-depth understanding of individuals’ subjective realities and experiences, and involves turning a specific study into a series of representations including field-notes, interviews, photographs and memos to the self (Denzin & Lincoln, 2000:3). A qualitative approach is a way of examining the “how” and “why” of a phenomenon studied not just what, where, when or who (Denzin & Lincoln, 2000:3). It aims at making sense of and interpreting the phenomena which are explored according to the meanings people attach to it. The aim of the present study, which explores flourishing among individuals diagnosed with HIV/AIDS, is to achieve an understanding of each participant’s case and his or her subjective thoughts, views and experiences of flourishing after finding out about their diagnosis, and a qualitative approach is well-suited to this type of exploration of subjective phenomena (Welman et al., 2005:7).

1.7.3 Ontological philosophy

Ontology is a term that is used to refer to the assumptions made about the nature of (in this case, social) reality (Crix, 2002:176), and includes what we believe to be reality and what is out there to know. An interpretivist ontology will be used in the present study. The exploration of flourishing amongst individuals diagnosed with HIV/AIDS in South Africa is concerned with subjective realities of participants. An interpretivist ontology assumes that knowledge and meaning are acts of interpretation and that there is no objective knowledge which is independent of thinking, reasoning humans (Cuba & Lincoln, 1989:83). This implies that phenomena will be understood through meanings that people assign to it (Cuba & Lincoln, 1989:83). The study of flourishing among individuals diagnosed with HIV/AIDS is concerned with individuals’ subjective experiences, perspectives, and views in relation to their own well-being. As such, an interpretivist ontology is ideally suited to explore these participants’ realities from an ‘insider’, subjective point of view.

1.7.4 Epistemological philosophy

Epistemology is concerned with how one can know about the reality that is spoken of in ontological philosophy (Crix, 2002:177). Therefore, it refers to the theory of knowledge - the methods, validity and possible ways of gaining knowledge of social reality and what it is understood to be. Social constructivism served as epistemological foundation for the current research, which focuses on exploring flourishing amongst individuals diagnosed with
HIV/AIDS. This approach acknowledges that there exists multiple, socially constructed realities in relation to the research topic, which are explored through shared investigation by both the researcher and the participants (Ritchie & Lewis, 2013:13). In this study, the researcher wishes to explore the subjectively constructed accounts of flourishing among HIV positive individuals.

1.8 Research design

The general aim of this study is to explore and also understand how and why some individuals diagnosed with HIV/AIDS flourish in spite of the fact that many others are just barely coping or not coping at all. The study is therefore qualitative and exploratory (Maree, 2007:267). To achieve a rich understanding of the lives of HIV/AIDS diagnosed individuals who are flourishing, the researcher needs to go deeper into their world. A case study of each participant would help to obtain an in-depth understanding of their experiences, feelings and thoughts (Zach, 2006:5). A single case however would not have yielded an understanding of the commonalities or differences there might be between the participants (Zach, 2006:9). A multiple case study design addressed these limitations as it meant that conclusions gathered from one case should be compared and contrasted with the results from the other cases (Bengtsson, 1999:9). Multiple case study designs generally involve the study of various units within identifiable cases (Bengtsson, 1999:9). Conclusions from case studies alone are not enough, so multiple case studies typically yield more robustness to the conclusions of the study (Bengtsson, 1999:2). The conclusions drawn from one individual flourishing whilst diagnosed with HIV/AIDS have therefore been compared with the results drawn from the other cases to provide a more credible set of findings, as is typical with this type of approach (Bengtsson, 1999:2; Zach, 2006:9).

1.8.1 Participants and sampling

As the study is qualitative in nature, a purposive sampling method was used. More specifically, in identifying and recruiting participants needed to fulfil the purpose of the research study, an extreme case sampling method was used. This method entailed purposefully selecting those individuals diagnosed with HIV/AIDS who are doing exceptionally well despite the diagnosis. Extreme cases represent participants exhibiting clear-cut and unique instances of a phenomenon a researcher is interested in (Palys,
In line with the purposive sampling strategy that has been adopted, the following sampling criteria were set for the study:

- Firstly, participants should be diagnosed with HIV/AIDS, and should have been aware of this diagnosis for at least two years or more.
- Second, the participants must (through the records provided) show a stable CD4 count (not a drop below 200 or otherwise), that will help in determining whether the participant is likely feeling good and functioning well in their lives. This strategy was adopted on the basis of the fact that CD4 count levels of less than 200 generally mean that there is damage in the immune system, which likely (though by no means certainly) indicates that the individuals are likely not functioning well in their lives. Conversely, a higher CD4 count is associated with better well-being (Sabin & Phillips, 2009: 193).
- Third, participants must be identified by some health care professional (such as a medical doctor, psychologist, professional counsellor, social worker, etc. who is familiar with the participants’ case history) as flourishing. The identification of flourishing participants by the health professionals was deemed as a workable (though admittedly not perfect) strategy given that they have been monitoring the progress of their patients from the time of diagnosis, and are therefore familiar with the patient’s level of functioning to some degree. By combining CD4 count information with the recommendations of health care professionals as well as the self-reported incidence of flourishing by the participants, the likelihood of obtaining participants who are truly flourishing is significantly enhanced.
- Fourth, the participants must be accessible from the records of the Tokollo Hospital, where the study will be conducted.
- Lastly, participants must be older than 18 years of age.

Data were collected in Heilbron at the local hospital, namely Tokollo Hospital, as this hospital is accessible to the researcher. Though a small town in the Free-State, this hospital provides health services for 2 other neighbouring towns, namely Petrus Steyn and Edenville, and as such, is the primary provider of HIV/AIDS related services in the region. Tokollo Hospital is a community hospital and the only hospital in Heilbron, though there are a number of clinics too. The hospital is situated in town, which is not far from the township. It is situated in a quiet neighbourhood, with good security and dedicated staff. Patients at this
hospital are predominantly black, with significantly smaller numbers of coloured patients, and an even small number of white patients.

1.8.2 Data collection

Semi-structured interviews were used in order to acquire the required data from the participants who were selected. Interviews are usually conducted with people to find out from them those things that cannot directly be observed. Patton (2002:341) suggests that the purpose of an interview is to allow the interviewer into the perspective of the other person. Semi-structured interviews are appropriate when aiming to explore the perceptions and also opinions of respondents, and are commonly used in the context of qualitative research (Barriball & While, 1994:330). This method of data gathering enables researchers to understand complex and also sensitive issues, and also enabling them to probe for clarification and more information (Barriball & While, 1994:330). As such, this data collection method was deemed to be well-suited to the exploratory nature of the present study.

1.8.2.1 Questions used to guide the interviews

Semi-structured interviews are commonly facilitated by means of an interview guide, which is comprised of a series of (usually open-ended) questions pertinent to the research topic (Tracy, 2013:131). In the case of exploring flourishing amongst individuals diagnosed with HIV/AIDS open-ended questions were asked in order to elicit lengthy and meaningful responses from the participants. Open-ended questions give the researcher the ability to learn the interviewees’ thoughts and judgements, and also capture the complexities of his/her individual perceptions and experiences (Patton, 2002:348).

The following questions guided the interviews.

Question 1: What are the factors that contribute positively in your life and enable you to do so well in life despite your diagnosis?

Question 2: Why would you say that you feel good and function well in your life?

Question 3: What, if anything, do you do to make sure that you are healthy emotionally and physically?
Question 4: Do you have any goals you plan on achieving in your life, and if so, how are they different from before you knew your status? Why is this?

Question 5: Have you ever encountered any stigma and/or discrimination from others because of the disease? If so, how did you deal with this? (If participants were found to be able to maintain a positive attitude despite such stigma, they were asked to explain how they managed this).

Question 6: Knowing that you are living with HIV/AIDS, what enables you to still say that you are doing well/satisfied with your life?

Question 7: Now that you know that you are living with the disease, how do you see the future? What plans do you have?

Question 8: When things are not going well for you, what do you normally do to get back on your feet?

Question 9: What gives your life meaning/purpose? How do you sustain this meaning?

When conducting the interviews, care was taken to ensure that no question was phrased in a way to suggest that one answer is more likely or preferable to another answer. In order to get clarity, completeness or additional information, additional probing was used as necessary. A probe is generally used to encourage the conversation without the interviewer influencing the answer (Patton, 2002:348). Examples of probing questions that were asked include:

“Can you explain more?”

“What do you mean by…?”

“What other reasons do you think contribute to…?”

1.8.3 Research procedures

As soon as permission was received to work at Tokollo Hospital from the CEO of the hospital (see Appendix A), formal permission to conduct the study was sought and obtained from the NWU Human Health Research Ethics Committee (see Appendix B). The head social worker was then approached to assist with the identification of patients who exhibit indications of flourishing. The aim and what the study is about were thoroughly explained to all prospective participants, and they were informed as to how the study was to be conducted,
how long the interviews would take and were given extensive information about the ethical matters related to the study. The informed consent forms (see Appendix C) were handed out to the participants after these explanations, and they were given a cooling down period of 24 hours in order to decide on whether or not they wished to take part in the study. Once the signed informed consent forms had been obtained, the interviews were then conducted at Tokollo Hospital (in the office of the social worker, which was quiet, private, and free from distractions) at a time that was convenient to the participant. This typically coincided with their regular visits to the clinic, so as to avoid a situation where the participants had to incur any additional travel expenses. In some cases however, participants expressed the wish to be interviewed at their homes, in which case the researcher conducted the interviews at the participant’s residence at a time that was convenient for them. The interviews were recorded electronically (with participant consent) and the recorded data were transcribed and subjected to thematic qualitative analysis. The data gathering and analysis were done iteratively until theoretical saturation is achieved.

**1.8.4 Quality assurance**

In order to enhance trustworthiness and also quality-based research, the researcher sought to adhere to a number of important criteria of trustworthiness, which include credibility, transferability, dependability, and confirmability.

**1.8.4.1 Credibility**

Credibility refers to the internal consistency of findings about a phenomenon, how rigour is maintained and how the researcher communicates how he or she was able to do so (Morrow, 2005:252). Credibility in the current study was ensured by reflexivity, which entailed keeping reflective notes in which the researcher reflected on her own position in the research as well as the research process itself. This was followed by member checking where the researcher returned to the participants and verified findings with them. Finally, linking the findings of the study to other research findings was done, following the recommendations outlined by Morrow (2005:252).
1.8.4.2 **Transferability**

Transferability means that the findings of one study can be applied to other situations (Shenton, 2004:69). Although every case might be unique it is also an example within the broader group (Shenton, 2004:69). So for transferability to be achieved in this study, I, the researcher, sought to provide sufficient information about myself as an instrument, and the research context, the process, the participants and relationship with the participants in order to enable the reader to make an informed decision as to the extent to which the research findings might be transferable to the contexts they are seeking to understand (Morrow, 2005:252).

1.8.4.3 **Dependability**

Dependability implies that the study at hand should be conducted in a way so that it will be consistent across time, researchers, and the data analysis techniques that will be used (Morrow, 2005:252). This means that if the work were to be repeated, in the same context, with the same methods and with the same participants, similar results would be obtained (Shenton, 2004:71). In order to ensure dependability in the study at hand a detailed description of research activities and processes were provided. Factors influencing all stages of the research process have been clearly outlined.

1.8.4.4 **Confirmability**

Confirmability implies that research is never objective and it addresses the core issue that findings should represent the situation being researched rather than the beliefs of the researcher and also not the researcher’s biased interpretations (Morrow, 2005:252). Confirmability in this research has been accomplished by means of recording and creating verbatim transcriptions of the interviews and by providing quotations from the interviews to illustrate findings. Member checking further served to mitigate the likelihood of biased interpretations of the results.

1.8.5 **Data analysis**

Data analysis methods help to describe facts, detect occurring patterns, and develop explanations. Judd *et al.* (1991:360) elaborate on this by saying that the purpose of analysis is
to summarise the data that were observed and collected to such an extent that they answer the research questions. Data can be analysed in different ways to achieve sensible results, and the method of data analysis that was used in this study was inductive thematic content analysis. More specifically, the researcher followed the processes proposed in Braun and Clarke (2006:87) in conducting the analysis. The researcher listened to the audio recordings from each participant’s interview and transcribed it word for word. Following the transcription process, the researcher read through the textual data several times, and then the data was segmented according to the units of meaning they contained, and subsequently coded. This involved assigning a descriptive label to the text that describes the essence of the segment of text as it relates to the research topic. The identification of codes was refined several times in order to generate a coherent and comprehensive set of codes. All the codes that were redundant were deleted and/or merged with other codes as appropriate. Codes that exhibited a high degree of conceptual overlap were similarly merged. After identifying the meaningful codes on the text, the researcher grouped the codes into meaningful categories and overarching themes that encapsulated the essence of the study’s findings.

1.9 Ethical considerations

Qualitative research entails close contact with humans, and consequently such interactions might elicit unwanted personal feelings and memories. As such, Brinkmann and Kvale (2008:269) state that ethical issues are a crucial part of the research process from conceptualisation to finalisation. This is especially so in the present study as the topic of HIV/AIDS is particularly sensitive. Vulnerable people, who disclosed personal details about their lives, participated in the research. When dealing with such participants, it is proposed that the researcher should also obtain permission, do research of high quality and share their results after the research (Brinkmann & Kvale, 2008:269), as has been done in the present study.

Exploring flourishing amongst individuals diagnosed with HIV/AIDS is a sensitive matter because personal information will be disclosed to the researcher (Welman et al., 2005:195). There are usually three stages when conducting a study where ethical considerations come into place: when participants are recruited, during the intervention, and when the results are released (Welman et al., 2005:181). Four ethical considerations fall into place when working with human participants namely: informed consent, the right to privacy, protection from harm, and the involvement of the researcher (Welman et al., 2005:201). The study of
exploring flourishing amongst individuals diagnosed with HIV/AIDS followed ethical processes usually followed in social research aimed at addressing these ethical considerations (Huysamen, 1994:180).

The hospital was approached to inquire about conducting the research there. The researcher therefore disclosed the objectives, the topic and the aim of the research to the management of the hospital (Welman et al., 2005:195). Written permission was obtained from the hospital to conduct the research (Welman et al., 2005:195). The study required a closed venue and a place where participants could freely express themselves without concerns of being overheard in order to ensure confidentiality. Therefore, a closed venue was provided by the hospital in an office used by the social worker at the hospital. The participants were given necessary information about the topic and the aim of the research at hand and also what the researcher aims to accomplish with the research at hand (Welman et al., 2005:201). The information was issued prior any interviews. Potential participants were then explained to that they would be provided with a consent form which would be signed by those participants who agree to take part in the study. As is typical of such documents (Patton, 2002:407), the consent form highlighted the purpose of collecting the data; who the information is for; how the information will be used and what will be asked in the interviews; how confidentiality would be assured and what the risks and benefits associated with their participation in the study were. It was also clearly explained to potential participants that they were free to withdraw from the study at any given time (Patton, 2002:407).

The signed informed consent letters were retained as proof that the participants agreed to take part in the study and also they understood all that was explained to them about the study at hand (Patton, 2002:409). Following signed consent, interviewing took place. The participants were free to make judgements about the nature of the questions asked and judged for themselves if they were comfortable in answering them (Patton, 2002:407). The password protected recordings and transcripts of the interviews were subsequently securely stored on the researcher’s laptop. The participants who have opted so will receive feedback on the findings of the study. The participants were assured of confidentiality explaining that their names and identities will not be disclosed in the final mini-dissertation or in any other context (Welman et al., 2005:196).
1.10 Chapter division of the mini-dissertation

This dissertation will be written in the article format (as approved by the NWU), and will comprise the following chapters:

Chapter 1: Introduction, problem statement and objectives

Chapter 2: Article: A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa

Chapter 3: Conclusions, limitations and recommendation

1.11 Summary

The aim of this introductory chapter was to provide contextual information relevant to the study on which the mini-dissertation is based. The chapter began with a review of the HIV/AIDS disease and its impact in the lives of the individuals diagnosed, followed by an overview of the term flourishing and the factors that contributes to flourishing. Next, the research aim guiding the study was outlined, which involves the exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa. Following this, the ontological, epistemological, and theoretical frameworks guiding the study were discussed. Then, the methodology that was followed in the study was outlined, after which ethical issues pertinent to the study were discussed. The findings for this study are presented in a research article format (which is in accordance with the article format as specified by the NWU) in the next chapter. Finally, the third chapter comprises of a detailed summary of the implications, limitations, recommendations, and reflections relevant to the study.
REFERENCES


CHAPTER 2

RESEARCH ARTICLE
A QUALITATIVE EXPLORATION OF FLOURISHING AMONG INDIVIDUALS DIAGNOSED WITH HIV/AIDS IN SOUTH AFRICA

ABSTRACT

The main aim of the study which informed this article was to qualitatively explore flourishing among individuals diagnosed with HIV/AIDS. Semi-structured interviews with 15 purposively selected flourishing HIV positive participants (7 male, 8 female), and who made use of Tokollo District Hospital in the Free State province of South Africa as their health care facility, were used to gather data for the study. Data were analysed by means of thematic content analysis. Eight main themes emerged from the data, which served to account for how individuals diagnosed with HIV/AIDS in South Africa are flourishing despite their diagnosis. In particular, acceptance of their diagnosis; having a positive outlook on life; taking responsibility for their condition and adopting healthy lifestyle habits such as a good diet and regular exercise; drawing strength from religious faith and activities; having supportive social relationships; having a future orientation; motivating and encouraging others suffering from the same condition; and music were identified as those factors that contribute to flourishing among the participants. The article is concluded with the recommendation that more research be conducted to explore flourishing among a more diverse sample of HIV positive individuals. It is recommended that the findings of the study be considered when developing interventions or providing training for HIV counsellors in order to assist patients who are languishing as a result of their diagnosis.

Keywords: flourishing, well-being, HIV/AIDS, South Africa
2.1 Introduction

Being diagnosed with HIV typically brings about negative consequences in a person’s life, not only on a physical level, but also mental health conditions such as depression and anxiety. Moreover, being HIV positive can have a negative impact on various parts of persons’ lives. For example, they could become overwhelmed by the diagnosis, and commonly they experience a lot of negative emotions such as anger and fear (Gilbert et al., 2014:2). As such, HIV involves not only the body, but it may also adversely affect one’s emotional well-being, relationships, self-image, and behaviour (Cockerham, 2001:157). Despite this, a number of people living with HIV have proved to not only not be depressed about their status regardless of the many negative circumstances they might face, but to actively thrive in spite of their diagnoses (Russell et al., 2016:92; Mavandadis et al, 2009:93). Even with this, there is not much written about flourishing among individuals diagnosed with HIV/AIDS in South Africa. Therefore, there’s a need to explore flourishing among individuals diagnosed with HIV/AIDS in South Africa in order to support the development of effective programs to support HIV positive patients.

Several international studies have been conducted with regard to well-being, flourishing and the factors that signify flourishing in individuals (Van Zyl & Rothman, 2012:380). A few of these studies conducted internationally were on the well-being and flourishing of people diagnosed with HIV/AIDS. However, these studies tended to focus on specific sub-groupings among those diagnosed, were quantitative in nature, or did not explore flourishing among HIV diagnosed individuals (Huppert & So, 2013:840). Moreover, no studies could be located that examined this phenomenon in a South African context; and not many studies approached the topic from a qualitative perspective. The present study is thus aimed at addressing these gaps by undertaking a qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa.

2.2 Flourishing

Purported to be an end state in positive psychology, flourishing is a desired state by individual human beings, though some research argues its attainability (Keyes & Annas, 2009:199). Flourishing is an optimal state of well-being that involves more than merely the absence of ill-being. Flourishing is defined as having high levels of both hedonic and eudiamonic well-being (Keyes & Annas, 2009:198). The hedonic component consists of
subjective and emotional wellbeing, and how satisfied an individual is with his or her life, whilst the eudiamonic dimension represents the degree to which an individual is functioning well (Wissing et al., 2014:8).

Opposing flourishing there is languishing, where individuals are not functioning well in their lives (Cilliers & Flotman, 2016:3). In order to flourish, a person needs to be well emotionally, psychologically and socially (Basson, 2015:98). Persons who do not flourish are at a significantly greater risk of mental health problems than persons who do flourish (Keyes, 2002:212). Therefore, researchers across the world developed an interest in the concept of flourishing. In as much as there is an increasing interest with regards to flourishing, not much qualitative research has been conducted on how, if at all, individuals are flourishing despite being diagnosed with HIV/AIDS, particularly in an African context. Most research done on the benefits of well-being and flourishing originates from the United States of America (Keyes & Annas, 2009:199).

A study done in Europe with 43000 respondents suggests that there are three factors that determine flourishing (Huppert & So, 2013:850). The first factor identified represented positive emotions. The second factor is clustered into five dimensions namely: emotional stability, vitality, optimism, resilience and self-esteem. Then, factor three is comprised of engagement, competence, meaning and positive relationship (Huppert & So, 2013:850).

In addition, Keyes & Annas (2009) suggests that for an individual to be defined as flourishing they must possess positive psychological, emotional and social well-being. He defines each concept in terms of understanding if an individual is satisfied with their lives and why they are satisfied. The first construct, psychological well-being, suggest that an individual has positive relations with others, is willing to grow personally, is in tune with his/her environment, has a purpose for his or her life and exhibits full self-acceptance (Huppert & So, 2013:3). Ryff (1989) further indicates that psychological well-being can be identified by self-acceptance; positive relations with others, autonomy, environmental mastery, purpose in life and personal growth.

The second construct, social well-being, occurs when individuals experience a sense of fitting in well in their communities. This means that an individual should be aware of their environment, be able to evolve positively, have positive relations with others, and have a positive attitude and perceived evaluation towards their society (Van Zyl & Rothman, 2016:140).
The third construct, emotional well-being, is mostly indicated by the following three aspects which include the presence of positive affect, the absence of negative affect (which are referred to as an individual’s affect balance when considered comparatively), and perceived satisfaction with life (Keyes, 2002:212). In relation to health, emotional well-being promotes a healthy lifestyle such as increased physical activity and motivation for self-care (Ostir et al., 2000:473).

2.2.1 Well-being and flourishing among individuals diagnosed with HIV/AIDS

Being one of the global epidemics, HIV/AIDS affects people of different genders, races and ages (Lyons et al., 2016:7). People living with the disease are advised (from the time of diagnosis) to take care of themselves and maintain healthy lifestyles, which includes taking their medication to help with the process. In a study on resilience and flourishing among people living with HIV/AIDS, Lyons et al. (2016:7) found that in all cases of the gay men that participated in the study, there was a high level of positive well-being among them despite the challenges of living with their diagnosis.

Furthermore, a study by Mavandadis et al. (2010:92) in Philadelphia explored psychological well-being among individuals ageing with HIV, and also examined the value of social relationships. The study utilized a heterogeneous sample of adults diagnosed with HIV infection, seeking to explore associations among age, various dimensions of social support, and psychological and functional well-being. The authors found that older adults reported significantly lower depression symptoms, greater positive affect, and were less likely to report seeing a behavioural health specialist than their younger counterparts (Mavandadis et al., 2010:92).

On the other hand, a study done by Chi and Li (2013:2558) explored the impact of parental HIV/AIDS on children’s psychological well-being in Detroit, USA. The authors found that individual coping skills, trusting relationships with caregivers, and social support tend to protect children against the negative effects of parental HIV/AIDS. Moreover, risk factors that might cause negative outcomes were suggested to be stressful events, stigma and poverty (Chi & Li, 2013:2558).

Another study conducted by Russell et al. (2016:3) examined self-management and well-being among HIV diagnosed individuals. The study was conducted with 38 people living with HIV in Uganda’s Wakisa district. The findings revealed that the health of people living
with HIV as well as the sustained success of antiretroviral therapy programmes depend on the motivation and ability of patients to self-manage the condition over a long term, including adherence to drug-regimens on a daily basis. Furthermore, the authors indicated that successful management of HIV sustains well-being, and that well-being is in turn likely to motivate continued self-management (Russell et al., 2016:2). Even though the authors found that many participants who were involved in the study were struggling economically, the recovery of their functional health and the hope they placed on anti-retroviral treatment had enhanced their well-being and increased their motivation to engage in effective self-management (Russell et al., 2016:2). Moreover, the authors found that the majority were managing well across different domains, namely, mobilizing resources through good relationships with health workers, and also, developing a network of support through contacts received at the antiretroviral clinic (Russell et al., 2016:2).

2.2.2 Well-being and flourishing in South Africa among HIV positive individuals

Mental illness has become the second largest disease burden in the world. Languishing persons have a greater chance to develop a mental illness than flourishing persons with a history of mental illness. Flourishing and moderately mental healthy individuals have been found to generally exhibit high levels of psychological functioning (Basson, 2015:65). In South Africa, it has also been found that flourishing individuals function better psychologically than individuals who are languishing or are moderately healthy (Basson, 2015:89).

With the benefits of flourishing, it is consequently important to not only focus on negative aspects leading to languishing, but to explore and establish inherent capabilities of flourishing among HIV/AIDS diagnosed individuals in order to assist those moderately coping and languishing. Keyes (2008) as cited in Basson (2015:101) exclaims that there is a low rate of flourishing among adults in South Africa of about 20% of the population (Basson, 2015:98). However, currently, little information is available regarding flourishing of HIV/AIDS diagnosed individuals. As such, more information is needed regarding the prevalence of flourishing as well as the factors that contribute to flourishing among HIV/AIDS diagnosed individuals (Basson, 2015:86).

Flourishing has benefits for the individual, the society and the work place (Basson, 2015:101). Whether individuals flourish or not might be due to differences in their internal
strategies, which relates to the way they regulate their emotions or affect. Understanding the strategies used by flourishing HIV positive individuals might be of great value in the development of interventions aimed at supporting those who might be languishing. A number of studies have been done on the well-being of people living with HIV, with only a few studies specifically focusing on the topic flourishing among individuals diagnosed with HIV/AIDS internationally, in Africa, and specifically in South Africa. Furthermore, a significant amount of information that does exist in relation to the topic comes from personal articles written by individuals diagnosed with HIV/AIDS who choose to share their journeys. Amongst these, Smith (2012) writes positive stories of HIV/AIDS diagnosed individuals who have been living with the illness for years but are living testimonies of leading positive and healthy lives. After more than a decade of living with HIV, Britt, one of the cases presents exclaims that “HIV is not a death sentence and people should stop thinking their dying when diagnosed”. In another example, Cullinan (2003) in an article on flourishing and compassion describes how diagnosed individuals use their voices in a choir to pay for their treatment and making a living to stay healthy and support their families. However, despite these anecdotal accounts, comparatively little research has been conducted in relation to how, if at all, individuals diagnosed with HIV/AIDS are flourishing despite their diagnosis. As a result, little is known about the factors that contribute to flourishing in HIV/AIDS diagnosed individuals in South Africa. Additionally, most studies conducted on the topic were either for specific groups such as gay men (Lyons et al., 2016:1658) or older adults (Mavandadis et al., 2009:92), or were conducted by means of a quantitative methodological approach. Employing a qualitative approach to this study would be of value as it would enable participants to express their lived realities and thoughts as HIV/AIDS diagnosed individuals. Findings from such a study would shed light on the factors that contribute to flourishing among HIV/AIDS diagnosed individuals, which is much needed considering the high concerns of stigma and discrimination affecting their lives in communities. Moreover, the research findings could be of value in establishing those inherent attributes of flourishing HIV/AIDS individuals, and using these in encouraging health professionals to optimize their strategies in working with defaulting and languishing individuals. Therefore, the aim of this study is to qualitatively explore flourishing among individuals diagnosed with HIV/AIDS in South Africa.
2.3 Methodology

An exploratory qualitative design was used as basis for the study. The researcher adopted a qualitative design for the aim of exploring and also understanding how and why some of the individuals diagnosed with HIV/AIDS flourish whilst others are just barely coping or not coping at all. Qualitative research collects, analyses, and interprets participants’ observations, thoughts, and experiences in order to understand and describe meanings, relationships and patterns (Tracy, 2013:36). Qualitative research is an appropriate approach for this study, because it will capture the realities, the meanings, experiences, and the views of participants. Qualitative date gathering methods will also enable participants to express their thoughts, perceptions, understanding, and identification of barriers in a more open-ended way than is typically the case with quantitative based research designs (Tracy, 2013:5). Qualitative research is well suited to uncovering salient, taken for granted, and unacknowledged issues regarding the phenomenon of interest (Tracy, 2013:5), such as flourishing among HIV/AIDS diagnosed individuals. Furthermore, such findings can later be studied using more structured methods (Tracy, 2013:5). Lastly, this kind of research method will provide the researchers and health professionals the opportunity to obtain a clearer perspective as to what flourishing participants actually do, what their values are, and how they live out these values on a daily basis (Tracy, 2013:5).

2.3.1 Participants and sampling

After permission was granted from Tokollo District Hospital to conduct the research at their institution, a total of 15 participants (7 men and 8 women) were recruited and interviewed. The participants in this study were women and men who are diagnosed with HIV/AIDS, and who are residing in the Free-State province in South Africa. Data was collected at a local hospital in Heilbron known as Tokollo District Hospital. Though a small town in the Free-State, Heilbron serves to provide health services for 2 other neighbouring towns namely Petrustyn and Edenville. Therefore, in addition to being accessible to the researcher, Tokollo Hospital was a well-suited place to find participants who are also HIV/AIDS patients with records of progress from time of diagnosis. This was deemed important as the recruitment process focused on those individuals diagnosed with HIV/AIDS who seemed to be doing well despite the diagnosis.
A non-probability sampling method (Doherty, 1994:25) was used to obtain participants for the study. Purposive sampling was used to select participants for the study. More specifically, in identifying and recruiting participants needed to fulfil the purpose of the research study, the researcher used an extreme case sampling method. Extreme cases represent participants exhibiting clear-cut and unique instances of a phenomenon a researcher is interested in (Palys, 2008:697). Specifically, in the present study the aim was to explore flourishing among HIV positive individuals, which necessitated that participants had to exhibit signs of flourishing. As is customary when employing any form of purposive sampling, a number of sampling criteria were specified prior to the study to guide the sampling process:

- Firstly, participants should be diagnosed with HIV/AIDS, and should have been aware of this diagnosis for at least two years or more.
- Second, the participants must (through the records provided) show a stable CD4 count (not a drop below 200 or otherwise), that will help in determining whether the participant is likely feeling good and functioning well in their lives.
- Third, participants must be identified by some health care professional (such as a medical doctor, psychologist, professional counsellor, social worker, etc. who is familiar with the participants’ case history) as flourishing, based on their progress from the time of diagnosis.
- Fourth, the participants must be accessible from the records of the Tokollo Hospital, where the study will be conducted.
- Lastly, participants must be older than 18 years of age.

Details of the participant group, which was comprised of 7 black males and 8 black females, are shown in Table 1.
Table 1: Profile of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Years diagnosed</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Male</td>
<td>3 years</td>
<td>Black</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>5 years</td>
<td>Black</td>
</tr>
<tr>
<td>P3</td>
<td>Male</td>
<td>3 years</td>
<td>Black</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>4 years</td>
<td>Black</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>4 years</td>
<td>Black</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>3 years</td>
<td>Black</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>2 years</td>
<td>Black</td>
</tr>
<tr>
<td>P8</td>
<td>Male</td>
<td>4 years</td>
<td>Black</td>
</tr>
<tr>
<td>P9</td>
<td>Male</td>
<td>6 years</td>
<td>Black</td>
</tr>
<tr>
<td>P10</td>
<td>Male</td>
<td>6 years</td>
<td>Black</td>
</tr>
<tr>
<td>P11</td>
<td>Female</td>
<td>10 years</td>
<td>Black</td>
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<tr>
<td>P12</td>
<td>Female</td>
<td>12 years</td>
<td>Black</td>
</tr>
<tr>
<td>P13</td>
<td>Male</td>
<td>3 years</td>
<td>Black</td>
</tr>
<tr>
<td>P14</td>
<td>Female</td>
<td>4 years</td>
<td>Black</td>
</tr>
<tr>
<td>P15</td>
<td>Male</td>
<td>5 years</td>
<td>Black</td>
</tr>
</tbody>
</table>

2.3.2 Data collection

Individual face-to-face semi-structured interviews were used to collect data from the participants (Barriball & While, 1994:330). The interviews were conducted with the participants on a one on one basis, for the purpose of allowing their thoughts and experiences be expressed openly, whilst also imposing enough structure to facilitate the attainment of the purpose of the study. Additionally, semi-structured interviews were also deemed to be well-suited to exploring the perceptions and opinions of respondents. Probing for clarification and more information was done to understand complex and sensitive issues raised by the participants (Barriball & While, 1994:330). Most of the interviews were conducted at Tokollo District Hospital, while a few interviews took place at participants’ homes. These venues were convenient spaces where participants could freely and comfortably express their thoughts and experiences, as they were private, quiet, and free from any distractions. The interviews were guided by the following questions.
Question 1: What are the factors that contribute positively in your life and enable you to do so well in life despite your diagnosis?

Question 2: Why would you say you feel good and function well in your life?

Question 3: What, if anything, do you do to make sure that you are healthy emotionally and physically?

Question 4: Do you have any goals you plan on achieving in your life, and if so, how are they different from before you knew your status? Why is this?

Question 5: Have you ever encountered any stigma and/or discrimination from others because of the disease? If so, how did you deal with this? (If participants were found to be able to maintain a positive attitude despite such stigma, they were asked to explain how they managed this).

Question 6: Knowing that you are living with HIV/AIDS, what enables you to still say that you are doing well/satisfied with your life?

Question 7: Now that you know that you are living with the disease, how do you see the future? What plans do you have?

Question 8: When things are not going well for you, what do you normally do to get back on your feet?

Question 9: What gives your life meaning/purpose? How do you sustain this meaning?

2.3.3 Data analysis

The interviews that were conducted were recorded on an audio recorder, and were transcribed verbatim. This method was appropriate in this study as it was explorative and qualitative in nature. Once the researcher transcribed the data from the interviews, the available data was then analysed using thematic content analysis, following the procedure outlined in (Tracy, 2013:140). The process consisted of the researcher listening to the audio recordings from each participant’s interview and transcribed it word for word. Following the transcription, the researcher read through the textual data multiple times, and then the data was subjected to an initial phase of open coding. This involved assigning a descriptive label to the text that relates to the research topic and could answer the research questions (Tracy, 2013:140). The codes
were refined several times in order to provide codes that could accommodate views and similar perspectives from the participants. As such, coding was done in an inductive manner, and was not driven by any deductively derived coding scheme.

Towards the end of this process, which was repeated several times, all the codes that were found to be redundant were deleted, or merged with other codes with which they might have shared a conceptual basis. On the other hand, codes that were found to be applied a large number of times were split into sub-codes. Following the initial coding process, the researcher categorised similar codes together. In turn, some of these categories were grouped into overarching themes, and possible relationships between codes, categories and themes were explored. These themes derived from the codes formed the basis of the research findings (Barriball & While, 1994:330; Tracy, 2013:140).

2.3.4 Ethical considerations

Ethical issues are a crucial part of the research process from conceptualisation to finalisation (Richards & Schwartz, 2002:137). Ethical issues, therefore, were treated with utmost caution to not only protect the rights of the participants but also to ensure the researcher’s professional conduct. Ethical clearance was issued by the North-West University’s Human Health Research Committee (HHREC). This was followed by obtaining clearance by the Department of Health in the Free-state and also Tokollo District Hospital to conduct the interviews with their patients. This clearance was given to conduct interviews with patients diagnosed with HIV/AIDS who were identified as flourishing. Participants were recruited by means of the database of the Hospital, which in turn, was done by the social worker, chief doctor and administrator. The social worker as a health care professional with the assistance from the chief doctor and administrator acted as mediators in recruiting participants after a process of careful evaluation. The participants were given necessary information about the topic and the aim of the research at hand and also what the researcher aimed to accomplish with the study (Roberts & Indermaur, 2003:292).

Participants were explained to that they will be issued a consent form which will be signed by those participants who agree to take part in the study. Also, it was explained to participants that they were free to withdraw at any given time (Patton, 2002:407). The consent form highlighted the purpose of collecting the information; whom the information is for; how the information would be used and what would be asked in the interviews, and also outlined
issues related to confidentiality, as well as the risks and benefits involved with participating in the study, as recommended by Patton (2002:407). After the participants signed the letter of consent they were made aware that as the researcher has responsibilities they also have a responsibility. Clarifying of the participant’s responsibility indicated their significant role, their importance and the importance of the study. In particular, the participants had to answer the questions asked effectively and to the best of their ability, within the constraints of their right to refuse to answer any question which they deemed to be overly sensitive or inappropriate (Patton, 2002:409). After obtaining the signed consent forms, the process of interviewing each participant took place. The participants were free to make judgements about the nature of the questions that they were going to be asked, and therefore, judge for themselves if they were comfortable in answering them (Patton, 2002:407). The participants were assured of confidentiality, that their names and identities will not be disclosed in the final mini-dissertation or in any other context (Welman et al., 2005:196). In line with the suggestions of Patton (2002:409), the participants were also informed clearly that the only people who will have access to the data are the researcher and the supervisor. All gathered data have been stored on the researcher’s personal computer, with a password system used to protect data files. Moreover, backup to the data will be stored safely at the university, where it will only be accessible to the researcher and the supervisor.

2.4 Findings

The findings of the current study exploring flourishing among individuals diagnosed with HIV/AIDS in South Africa are evaluated and described in this section. A total of 8 themes were derived from the data, which suggest that there are a number of factors that contribute towards flourishing daily in the lives of HIV/AIDS diagnosed individuals. The identified themes included acceptance, positive outlook on life, taking ownership of their condition, learning more about the disease, not being influenced by others negativity, faith and religious activities, social relationships, social support systems, motivating and encouraging others, future orientation, and music.

2.4.1 Acceptance of the diagnosis

One of the primary reasons provided by participants diagnosed with HIV/AIDS in South Africa as a major factor enabling them to flourish was their acceptance of the diagnosis. This
involved acknowledging that they now had to live their lives with an incurable disease. In Participant 15’s words: “taba taba ke hore o tshwanetse o amohele, ha senna wa pele re bangata akere and onka ho batho ba bang ba phetseng hantle” (the main thing is to accept yourself, we are many and I’m not the first one with this disease. Again I learn from others who are living well with the disease) (Participant 15, interview, 27 April 2017). Participants reported that accepting their diagnosis enabled them to be more focused on their health, and less focused on the negative weight HIV/AIDS already carries in itself. This was expressed by one participant saying “first thing you have to accept, and then from acceptance you are free from it. When you are free from it you forget that you are HIV positive, then, you concentrate on life as it is”. (Participant 4, interview, 9 March 2017) Another participant mentioned “I have accepted that I’m HIV positive and I should not give up on this but I should only drink my medication not thinking negative thoughts about dying” (Participant 6, interview, 9 March 2017) she went further to express her acceptance by saying “I feel good because ke qadile pele ho I accepta before anyone else accepted me” (I started accepting myself before anyone accepted me). Acceptance seemed to be the first step taken by each interviewed participant, and represented the first act in the process of becoming positive minded and determined to lead a healthy lifestyle.

2.4.2 Positive outlook on life

Having accepted the incurable disease that they live with now, participants indicated that they need to think positively and look at life in a positive manner. Participants indicated that having a positive outlook on life meant that even though they cannot eliminate the disease within them, they can change their perception away from the old belief that HIV/AIDS is a death sentence. One participant expressed this notion by saying “knowing my status hore it’s not killing me, knowing hore I’m the boss of my body. The virus cannot kill me and knowing hore ke ka kgona jwang hore ke e defeate” (knowing that my status is not killing me, knowing that I’m the boss of my body… The virus cannot kill me…knowing how I can defeat it). The same participant went on to say “it’s not like it’s a death sentence, my life is still going on”. Yet another participant supported this by saying “my future is very bright” (participant 10, interview, 30 March 2017). Participant 12 expressed her positive outlook on life by saying that “batho ba enka ele life sentence kapa o tlo shwa, empa HIV nna hoya kanna e ruta batho hore ba kgathalle bophelo. Ba nke bophelo serious, ba seka bapala ka bophelo. So, HIV ha se nto eo o reng okay... haba qala ho njwetsa o tlo ula ekareng o
sentse o tlo hlokahala, mara the more o bua ka yona o na le batho bao o buang le bona, kekare ke the more o bang hantle. Ke moo o kgonang ho bona ha ke mong nthong ena, hona le batho babang bantse ba tshwana lenna ba nang le HIV/AIDS jwalo kanna” (people take it as a life sentence or that you going to die, but HIV according to me it teaches people to take care of their lives. That is, to take their lives seriously and not to take their lives for granted. So, HIV is not something you say okay...when you first hear of your diagnosis you think you are going to die, but the more you talk about it with people that you talk to, I’d say it’s the more you become alright. That’s when you’re able to see you're not alone in this, there are people who are just like you diagnosed with HIV/AIDS) (participant 12, interview, 26 April 2017). The participant went further to say “kena le di plan tse ngata bophelong baka ende nkeke ka tlohella HIV eng stope. Ha ke kuli, ke ntho e teng honna. Motho a kulang ke a utlwileng bohloko, a hospital. nna hake kuli ke ntho e mading aka” (I have a lot of plans in my life and I won’t let HIV stop me. I’m not sick, it’s something within me. A sick person is that one in the hospital in pain, I’m not sick it’s just the disease in my blood).

2.4.3 Taking responsibility for the condition

Another factor that determined flourishing among individuals diagnosed with HIV/AIDS is taking responsibility for their condition. Preceded by acceptance of their condition, participants indicated that taking responsibility for their conditions means being aware and also learning more about the disease to empower themselves. One participant exclaimed this by saying “knowing hore I’m the boss of my body, the virus cannot kill me and also knowing hore ke ka kgona jwang hore ke defeate. Like eating healthy neh..., and protective sex, and being open to my partner, and having one partner” (knowing that I’m the boss of my body, the virus cannot kill me and also knowing how to defeat the disease) (Participant 4, interview, 9 March 2017). Another added “kena le boikarabelo, ka itjwetsa hore ere ketswe dinthong tse ding tsa tsona ke shebane le bophelo baka” (I have the responsibility, I tell myself that I should get out of some negative activities and focus on my life) (Participant 3, interview, 13 February 2017). Included in the theme of taking responsibility for their condition, was a sub-theme of healthy living, which participants regarded as being comprised of maintaining a healthy diet, exercising, and adhering to their medication regimen.
2.4.3.1 Healthy living

This sub-theme emerged frequently from each participant indicating that healthy living is a way of taking responsibility for their condition and of accumulating strength both emotionally and physically. Participants indicated that keeping healthy means maintaining a healthy diet (healthy food, drinking water and medication), exercising (taking walks and gym), and regularly taking their medication. Diet, however, was emphasised by participants far more than exercise. One participant exclaimed “HIV takes you back to being original, eating healthy stuff. So I’m having myself a diet, eating veggies and most of the time raw veggies tse kgonang ho jewa dile raw” (those that can be eaten raw) (Participant 4, interview, 9 March 2017). Another went further to say “ke motho a ratang honwa metsi haholo, ke bona ele ona a nthusang” (I’m the type of person that enjoys drinking water a lot, I believe they help me a lot) (Participant 2, interview, 8 February 2017). The importance of adhering to their medication regimen was attested to by this participant who stated: “I should only drink my medication, I should not...kore like keseke ka fetisa time or day not drinking my medication” (I should not let time or day pass without drinking my medication) (Participant 6, interview, 9 March 2017). Though not as frequently done, exercise was one of the activities said to be practised for healthy living. One participant expressed this, as well as the importance of taking medication, by saying “ke kena ka garage ke gyme, ke nahana gym le meriana eo re e sebedisang dia tsamaisana tseleng” (I go into my garage and gym, I think gym and the medication we use go hand in hand) (Participant 3, interview, 13 February 2017). Another participant said “I exercise with long walks, again also, part of my exercise if I get a chance we also have a program called Esibindi (courage) as part of exercise” (Participant 6, interview, 9 March 2017)

2.4.4 Faith/religious activities

One of the primary factors reported to support flourishing among individuals diagnosed with HIV/AIDS is their strong faith and the religious activities they practice. Findings of this study revealed a shared commonality among participants with regard to faith and religious activities, how keeping their faith and practising some religious activities increases their sense of well-being, hope and optimism. Faith and religious activities were divided into three sub-themes which include praying, reading the bible, and viewing God as the source of life.
2.4.4.1 Praying

This sub-theme was commonly shared by the participants as a religious activity that helps them to keep their faith when things seem to not be going right, or just for strength to endure. One participant asserted the importance of prayer in her life when she said “so, kea bua haholo in praying hore even if ke feela hore I need to give up, but then ke feela hore yah ore ke give upe, but ke kope matla” (I talk a lot in praying that even if I feel that I want to give up, I then ask God for strength) (Participant 6, interview, 9 March 2017). Another participant went further to say “ha dintho di ntsamaela hampe bophelong ntho ya pele ke ho rapela” (when things are not going well in my life the first thing I do is to pray) (Participant 12, interview, 26 April 2017).

2.4.4.2 Reading the Bible

Reading the Bible also emerged as a religious activity that assists participants in remaining motivated and driven to face their challenges in life. One participant expressed this by saying “kena le di healing verse tseo ke dulang ke di bala. Ke ne kele motho a ratang ho bala bebele haholo, ke ha ke tla utlwisisa hore lentswe la Modimo leya phela ha ole follow apa” (I have healing verses that I always read, I was the kind of person that read the bible a lot. That’s when I understood that the word of God lives when you follow it up) (Participant 2, interview, 8 February 2017). Another continued further to say “I think just sitting down and contemplating something in my mind, and create scenarios and try to figure out what’s been written, because first of all when the bible was written it actually seemed like there are so many meanings in it. Every line has got more than one meaning, so when you read a verse you need to contemplate it. When I think about it, I apply it to my life and how would it apply to a situation like this. “Oh so this is what it means if I do this?” I think it motivates me to the point where I can actually link spirituality which is something we do not actually see the physical world” (Participant 1, interview 2, 28 March 2017).

2.4.4.3 Viewing God as source of life

This sub-theme centres on the way in which the professed faith of the participants enabled them to flourish in spite of their condition. Many expressed the view that the diagnosis is not bigger than their God. One participant exclaimed that by saying “modimo ke ena a entseng
dintho tsohle, hotjhong le di Doctor ha dintse di re thusa ke Modimo a di fileng bohlale boo” (God is the one who created all things, meaning even the doctors helping us, where given the wisdom by God) (Participant 2, 8 February 2017). She added further to say “hobane Modimo lentsweng la hae o re ke yena a fodisang malwetse ohle” (because God in his word says he is the one that heals all diseases) (Participant 2, interview, 8 February 2017). Another participant added to say “I’m always praising God because he’s the one who’s leading us, He is our light”. The relationship and belief that God is the source of life gives the diagnosed individuals strength in their conviction that there is a higher power taking care of them and their every situation.

2.4.5 Social relationships

This theme also came up with nearly the same frequency as having a good relationship with God, indicating that diagnosed individuals seem to do well emotionally and physically when they have someone to live for and/or support, and/or when they have people who support them. This theme showed commonalities between the participants when they indicated how social support helps them bear the burden of their diagnosis. One participant expressed the value of support by saying “emotional support is important, especially from people around that can talk to people, you can trust people that understand you and know you. People who won’t judge you when they talk to you, who will be like “how did you do that or something”. Saying okay if you wanna do that, so I know that people in my life. I have those people in my life, I think I use that kind of emotional support to get back and pray” (Participant 1, interview, 2017). In another interview, a participant said “hona le batho ba tlisang dintho tse hantle bophelong, ere ha o bua lebona o bone hore motho ona ong ahile ere ke phahame ke seke ka nyahama. Ha se pheletso ya lefatshe” (there are people who bring positive energies in life, when you speak to them you feel empowered and you tell yourself you need to get up and not give up because it’s not the end of the world) (Participant 13, interview 26 April 2017). Another participant said “Ha ona le motho a o sapotang statuseng sa hao, ntho engwe le engwe e simple” (when you have someone to support you with your current status, everything becomes simple) (Participant 14, interview, 27 April 2017) Social relationship, as conceptualised within this theme, is comprised of the support received by family and friends, as well as taking care of family, which are discussed as sub-themes in the following two sections.
2.4.5.1 Family and friends support

This sub-theme emerged commonly from participants exclaiming that the support they get from family and friends provide a sense of emotional cushioning and shared burdens in relation to the stress and anxiety they might otherwise experience on a daily basis. One participant expressed this by saying “what makes me happy ke hore (is that), also my partner is positive and taking treatment. So, we are supporting each other. There’s nothing enkereng” (I would say) I’m hiding or he is hiding, we supporting each other through everything (Participant 4, interview, 9 March 2017). Another participant added to say “I have told two people, my mother and a lady from school. She encourages me, she also said her brother is HIV positive. But eat well and talk to us anything that you need, that’s why I’m calling her my spiritual sister”. While another participant exclaimed “I told my mother and that makes me strong” (Participant 6, 9 March 2017). Family and friends tend to bring about ease and encouragement to press on throughout the challenges of being diagnosed with HIV/AIDS.

2.4.5.2 Taking care of family

A fairly common reason put forward by participants for flourishing while diagnosed with HIV/AIDS is their love for family, whether it is starting a family of their own for those who do not have yet or taking care of children. One participant pointed out how being far from his children affected him by saying “kena le bana ke tshwanetse ke ba phelele, hape ke shebile hore bana baka ke pushe bona” (I have children I must live for, plus I’m working hard to see my children succeed) (Participant 13, 26 April 2017).

2.4.6 Government support

Several participants indicated that it was not only support in the context of social relationships that were helpful to them, but that support from the government also played a significant role in enabling them to flourish in spite of being diagnosed with HIV/AIDS. One participant expressed her gratitude for governmental support by saying “nna ho fihlela hona jwale ke tlare ke kgotsofetse, le hoya pele ke tlanne kere ke kgotsofetse. Hobane kannete mmuso o re thusitse ka di pilidi isena. Hoba ha ene ele hore dia rekiswa nkabe re nka tjhelete ena kae? Nkabe resena yona akere. Hoja ra seke ra zangelwa pilisi nyana tsena ke baba kae
“ba hlokahetseng” (I’d say up until today I’m satisfied, even going forward ill still say I’m satisfied. This is because really the government has helped us with these pills (ARV), because if they were being sold, where would we get the money? We wouldn’t have the money. If we were not considered for these pills, imagine all those that died before the pills) (Participant 13, interview, 26 April 2017). This suggests that larger scale governmental initiatives aimed at assisting those diagnosed with HIV/AIDS do, at least for some participants, translate into enhanced emotional (and not just physical) well-being.

2.4.7 Future orientation

A very prevalent factor that signified flourishing in individuals diagnosed with HIV/AIDS was their positive and optimistic outlook on the future. Participants generally indicated that they are optimistic about the future, and also that their goals were not changed by their circumstances, but rather that their diagnosis increased their urge to achieve them. One participant shared her goal saying “di goals tseo eloreng kea di hloka, tseo eloreng kea di batla is to be a social worker. The time ne ke qeta matric ka itjwetsa hore I wanted to be a social worker” (goals that I’m longing to achieve, goals that I’m hoping to achieve being a social worker) (Participant 6, interview, 9 March 2017). Another participant went further to stipulate her educational goals by saying “my plans are, 2018 I’m going back to school, from this year I’m going to rewrite my matric in June” (participant 4, interview, 9 March 2017). Another participant added to that by saying “Going back to school and being a psychologist, because that’s what I think. I think I’m sure now I wanna be a psychologist and studying psychology and finding a good job” (Participant 1, interview, 3 February 2017)

Education was not the only aspiration stated by the participants. Starting a family was one of the goals some participants stipulated despite them being diagnosed with HIV/AIDS. One participant said “I do plan to start a family, and obviously that goes with finding a job. Starting a family of no more than three kids” (Participant 1, interview, 3 February 2017). Most HIV/AIDS diagnosed individuals are not only hopeful for a healthy life but have aspirations to achieve success and make a good living for themselves and their families. As such, instead of having a demotivating impact on the participants, it appears that flourishing HIV positive individuals somehow manage to find a way to reverse this and construct the meaning of their condition in such a way that it becomes motivational.
Motivating and encouraging others

Another theme that expressed how participants diagnosed with HIV manage to flourish pertains to the urge to motivate and encourage others who are diagnosed too, or those who are young and not informed about the disease. Participants who were interviewed all emphasised their desire to live a healthy and positive life, which they hoped would serve as an example that will encourage others to not give up or think that their diagnosis is the proverbial end of the world. One participant expressed “ke batla ho bona ke fihlile mafatsheng a mang ke ba jwetse kere guys kena le boholo ho tjena ke phetse le bona lemo tse kana. Ke batla ha motho a nsheba a re wow hase nnete, motho ona o leshano ha hona ntho e jwalo. Then, beke tseba hore at least a le mong or ba babedi ba tlebe ba kgone ho utlwa. Ke tlise phethoho maphelong a batho bao ba babedi” (I want to see myself travelling to other countries and telling people that I have this disease and I’ve lived with it for years. I want them to look at me and not believe what I say from what they see. I want them to say I’m lying, I do not have that disease. Then, then I will know that at least one or two would be encouraged. I want to make a difference in the lives of those two people.) (Participant 7, interview, 9 March 2017). He further went to say “ke lakatsa ho bua le batho ba nang le bothata botje. Kebe mohlala wabona, eseng oboa hore motho ona leyena hoa haneha but ke be mohlala hore ke kgone ho bua motho a mamele a bone ntho e phelang” (I yearn to talk to people who have the same problem as I. To be an example to them, not to say this person also is having difficulties but to be an example so that I can talk so the person can hear and see what I’m living) (Participant 7, interview, 9 March 2017). Another participant exclaimed “nna haholo nka lakatsa ho thusa batho neh, hona le batho babang ba sokang ba ikamohela. O thole hore nna ke thola a sentse a nwa dipilidi mara yena ha a kgone ho phahama, ontse a le...kore be ke ipotse hore motho oo hanwa dipilisi ho hana ka bore a be hantle o kila bona. Nna ke pickapile ka sepiti hobane ke ile ka amohela, jwale eneka nka thusa batho babang lebona babane le ntho eno, a tsebe hore o santse a tlo phelanako e ngata lefatsheng mona. O tla nkuwa ke ntake modimo ha a batla eseng yena” (I would really like to help people, there are those people who haven’t accepted themselves. You would find that I found them already taking ARV’s, but they can’t be strong. They are still...then I ask myself why is this person not getting well but they are drinking their medication. I picked up very quickly because I accepted the diagnosis. So, I wish I could help other people so that they can also have that strength for them to know that they are still going to live long on earth. God will take you when he wants and not you) (Participant 14, interview, 27 April 2017).
2.4.9 Music

This last theme emerged from two participants, expressing the deep connection and also the deep spiritual enlightenment music provides for them which significantly supported them in feeling good and functioning well. This was expressed as follows in the word of Participant 1: “it’s got its own individual personality, like a certain song when you listen to it, it is sure to spark up a certain feeling”. He went further to say “for me playing music I get to deal with problems of the past and I get to focus on the now more, because I keep on repeating those same words that actually have an effect on me emotionally. So, by playing music and singing along the emotion starts of as an emotion were I cry maybe sometimes, the more I play the song the more I’m centred on the now and I lose the regret if it’s a regretful song, the more I lose the fear if it is a fearful song. So, I think music does that for me, it centred me into the present” (Participant 1, second interview, 2017). Music to the participant proved to help him cope with past and present unpleasant situations that he encountered in his life. Another participant added: “ha ke nahana hore ke tla tshwarwa ke stress nna, hai...nna ke i papilla radio ke ipapalle soud...hona le mmino wane o o thoulang stress, ha o mamela o fumane hore lewena o phodile, o ikutlwa monate” (I think whenever I feel stress, hai... I play my music on the radio. There is that music that relieves stress when you listen, you find you start becoming relieved and feel good.) (Participant 13, interview, 26 April 2017)”

2.5 Discussion

The aim of this study was to explore flourishing among individuals diagnosed with HIV/AIDS who are residing in the Free State province of South Africa. The approach taken for this study was qualitative in nature, with semi-structured interviews used to conduct interviews with 15 participants (8 females and 7 males). Inductive thematic analysis was used to analyse the data. Eight themes were derived from the data to indicate the factors contributing to flourishing among individuals diagnosed with HIV/AIDS.

The findings of this study indicated that the first step taken by participants towards emotional, social and psychological well-being was acceptance after diagnosis. This was done in order to continue living their lives despite their HIV/AIDS status. The participants in the study indicated that even though the diagnosis initially affected them negatively for some time after the diagnosis, accepting the diagnosis meant confronting new situations that required them to re-assess their lives and choose how to deal with such a situation. Bertolini
et al. (2006) confirmed this by stating that after diagnosis the psychological adaptation process begins in the diagnosed individual. Also, the level of dependence by a patient on a health professional is reduced when an illness is accepted as it reduces the need for persistent emotional support from health professionals. This was found to be prevalent in the shared experiences of the different participants, as they conveyed that their acceptance of the disease played an important role in enabling them to flourish in spite of their diagnosis.

It was further found in this study that taking responsibility for their condition enabled participants to flourish. The participants indicated that taking responsibility meant educating themselves, being aware of safe practices for sex, adopting a healthy lifestyle and also preventing defaults (e.g. on taking medication) that may occur. These findings build upon those reported by Bertolini et al. (2006:441), indicating that the importance of taking responsibility relies on regular exercise practices, a healthy diet, taking of medication and a periodic medical check-up. Other research also indicates that taking responsibility for improving one’s health results in improving lifestyle and quality of life, which will impact the overall well-being of HIV positive patients (WHO, 2003:68). These findings also indicated that individuals also felt a sense of control and increase in strength when they were diligent in their healthy lifestyle. The findings thus serve to lend further empirical credence to the recommendations proposed by the WHO (2003) who state that taking care of oneself whilst diagnosed with HIV/AIDS entails resting the body, managing stress, and keeping a positive attitude, exercising, and always seeking necessary advice from health professionals.

Participants indicated that accepting and taking responsibility for their condition meant maintaining a healthy lifestyle/healthy living. Participants explained that they understood a healthy lifestyle to mean eating healthy, taking their medication, and exercising regularly, and regarded these practices as playing an important role in their well-being. Though HIV/AIDS attacks the immune system, resulting in weight loss, fever, opportunistic infections (sore throat, tuberculosis, etc.), the WHO (2003) echoes these notions by indicating that eating nutritious food and drinking water helps to maintain energy, while exercising reduces stress, provides good night sleep, as well as increasing appetite among those suffering from this illness.

The findings from this study further showed that participants’ ability to flourish were significantly associated with their religious beliefs and activities (like prayer, meditation, reading religious literature, and church attendance). This finding is in line with existing
research that indicates that religious activities keep individuals grounded and also committed to their religion, promoting better and healthy behaviours like fewer intakes of harmful substances (alcohol and smoking) (Mattis & Jagers, 2001:522). McCoullough et al. (2000) as cited in (Elliot & Dweck, 2002:24) maintain that highly religious people have a 29 percent higher likelihood of being alive at follow-up than less religious people. Positive health benefits of prayer and bible reading have been reported by Sloan, Bagiella, and Powell (1998:341) as cited in Elliot & Dweck (2002:25).

The results from the study also indicated that social relationships play an important role in supporting participants’ ability to flourish. Interviewed participants often indicated that the support that they get from those they trusted with their diagnosis enables them to engage more in activities that allows them to live a flourishing life. In line with these findings, Cohen (2004) notes that social support is invaluable in enabling individuals to cope with stress, by means of allowing for expressions of empathy and emotional venting. He goes on to note that performing a wide range of social activities to promote self-identity, purpose, self-worth, and positive affect serve as additional predictors of well-being (Cohen, 2004:678).

Findings of this study revealed that another factor contributing to flourishing among individuals diagnosed with HIV/AIDS was adopting a future orientation. Participants expressed having goals of bettering themselves and improving things for others, going back to school to get their degrees, and also advancing into those jobs and careers that they have always dreamed of. Moreover, the findings indicated that participants also had health goals, where they expressed seeing themselves as healthy as possible without any complications even with the disease. The health goals set would give them more strength to set and achieve other, non-health-related goals. These findings agree with the statement made by Emmons and Rollnick (2001) that a person’s engagement in setting health and medical goals has been demonstrated to affect not only his/her participation in adherence to treatment, but also his/her health outcomes and quality of life (Emmons & Rollnick, 2001:70).

Several participants indicated that they intend to serve as living examples of healthy living despite diagnosis, and that they desire to bring about change in the lives of individuals who have lost hope. For most, these aims directly supported their ability to flourish, as it imbued their condition with a higher meaning. Keyes (2002) as cited in (Klar & Kasser, 2009:756) indicated in a study that activists are more likely to be flourishing than non-activists. Also, Seifert et al. (2012) expands on the existing findings by indicating that inwardly motivated
people do not need wellness initiatives, they will do it on their own, while also trying to help those who are not inwardly motivated adopt healthy behaviours.

Another finding from the study was that music contributes significantly to flourishing among individuals diagnosed with HIV/AIDS. The participants indicated that music reminding them of conquered negative past experiences and enables them to acknowledge and deal with present circumstances better. The lyrics of a particular song might bring deeper meaning and healing to them presently, than in the past. Kemper & Danhauer (2005) agree with the findings by exclaiming that music is a therapeutic energizer used to uplift the life of the listener based on experiences from the past, present conditions, and the desired future. Music has been noted to enhance well-being as it allows for direct physical effects through the autonomic nervous system (Kemper & Danhauer, 2005:286). Therefore, music therapy also benefits people in helping to reduce anxiety levels related to unpleasant experiences (Clark & Tamplin, 2016).

2.6 Implications of the findings

The findings of the study have a number of implications for theory and practice. In terms of theoretical implications, it is hoped that the findings will contribute to current understanding of the antecedents of flourishing among individuals diagnosed with serious chronic illnesses such as HIV/AIDS.

In terms of implications for practice, the findings of the study could be of use to counsellors, medical health care professionals and others working with individuals diagnosed with HIV/AIDS in a therapeutic capacity. Furthermore, the findings might also be of use in informing the development of interventions and programs aimed at enhancing the well-being and quality of life of HIV positive individuals. Such programs could include strategies aimed at assisting patients to move towards an acceptance of their diagnoses, and to adopt personal responsibility for managing their condition. The findings suggest that among religious patients, the faith of these individuals could be mobilised in the context of such programs as a powerful force in supporting them on the road towards flourishing. The findings also point to the value of social support, which could be facilitated in terms of patients’ families and friends as well as in the context of group based therapeutic interventions or programs. Such programs should ideally allow close family and friends to partake collaboratively in supporting the emotional well-being and healthy lifestyles with the patient. Once HIV
positive individuals have achieved some degree of well-being, the findings suggest that there might be great value in encouraging them to serve as advisor or mentor to other newly diagnosed or languishing HIV patients, as this might likely enhance the well-being of both parties. As such, interventions could be tailored to foster a higher perspective of the illness and constructing it as an opportunity to serve as an example to others. Allied to this would be that HIV positive individuals should be encouraged to develop a future orientation by setting and working towards personally meaningful goals, in order to live purposeful and driven lives.

2.7 Limitations and recommendations

A number of limitations occur in the study. Firstly, the research was done with a comparatively small sample of fifteen participants who were all recruited at a single hospital in Heilbron in the Free-State, which limits transferability of the findings to dissimilar contexts. However, several participants came from beyond the Heilbron area, which might serve to mitigate this shortcoming to some extent. Secondly, participants used in the study were all black African males and females who resided in relatively impoverished communities and as such, the findings would not necessarily transfer to other racial and/or socio-economic contexts. Based on these limitations, a need exists for additional quantitative research with a larger and more demographically representative sample in order to empirically quantify and verify the qualitative findings. This will enable determinations to be made in relation to the extent to which the findings made in this study might (or might not) be generalizable to HIV positive individuals from other racial, cultural, socioeconomic and geographical contexts.

Other recommendations for future research from the findings of this study suggest that more research should be conducted on the process from diagnosis and accepting their diagnosis in order to understand how patients negotiate this process. Such an understanding might be of significant value in assisting languishing patients to make the transition to acceptance of their diagnoses. More research should also be conducted on the impact of prayer, reading the bible, motivating others and music in assisting individuals to flourish. This will yield understanding on what counsellors and psychologist might include in their HIV/AIDS programs. Research on the role and value of goal setting among individuals diagnosed with chronic conditions like HIV will also be beneficial in further informing intervention strategies.


2.8 Conclusion

The main aim of this study was to qualitatively explore flourishing among a group of 15 South African individuals diagnosed with HIV/AIDS in the Free State province by means of semi-structured interviews, which were subsequently analysed by means of inductive thematic content analysis. Findings indicated that accepting their diagnosis was the first step that enabled most of the participants to move towards flourishing. Accepting their status enabled them to take responsibility for their condition, and for their overall well-being, in particular by adopting a healthy diet, engaging in exercise, and adhering to medication regimens. The findings of the study also revealed that all the participants had high levels of religious faith that keep them grounded and able to think positively, as another factor contributing to their flourishing. Moreover, being engaged in religious activities that allow for hope and positivity like praying and reading the bible were indicated by participants as practices that gave them strength in challenging times, and enabled them to flourish. Many also found strength in listening to music. Social support from family and friends also served as important antecedent of flourishing among the participants, as it made them felt that they were cared for, and also alleviated certain practical burdens. Furthermore, having and pursuing important life goals was a source of hope and flourishing for many participants. Among these, the goal to serve as an example to others imbued many participants with a sense of meaning, which further contributed to their capacity to flourish in spite of their diagnosis. In addition to contributing to the body of knowledge in relation to factors associated with flourishing among individuals diagnosed with HIV/AIDS, these findings might be of significant value in informing programs and interventions aimed at enhancing the well-being of those diagnosed with this condition.
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CHAPTER 3

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

3.1 Introduction

This chapter presents a summary of the findings of the study, conclusions drawn from the study, and implications emanating from the findings. The limitations or barriers faced during the research study process are discussed and suggestions for future studies are made at the end of the chapter. This chapter will be concluded by reflection of the research process by the researcher.

3.2 Conclusions

The present study aimed to explore the factors that contribute to flourishing among 15 individuals diagnosed with HIV/AIDS in a South African context. Previous studies conducted globally focussed on topics such as negative outcomes associated with HIV/AIDS, or nutritional care and support for people living with the disease (e.g. WHO, 2002:2; Piwoz & Preble, 2000). Other previous studies explored anti-retroviral therapy, and focused on those individuals finding it difficult to stick to their diet plan and medication regimens (Safren et al., 2002:478; Little et al., 2002:385). Other researchers examined satisfaction with social support, coping styles, and punishment beliefs about HIV/AIDS (Safren et al., 2002:478). Some other studies on flourishing and well-being included that on Australian gay men’s resilience and flourishing while living with HIV, and self-management and well-being of people taking ARV’s (Anti-retro-viral therapy) in Uganda (Lyons et al., 2016:4; Russell, 2016:3). However, very little research on flourishing among individuals diagnosed with HIV/AIDS has been conducted in South Africa. The main aim of the research was therefore to explore flourishing among individuals diagnosed with HIV/AIDS using a qualitative methodological approach. A purposive sampling method and extreme case sampling method was used to obtain participants for the study conducted (Patton, 1990:169; Palys, 2008:697). Based on the sampling criteria, participants in the study had to have been aware of their HIV/AIDS diagnosis for two years or more, and had to be flourishing (as identified by both themselves and an expert panel consisting among others, of their supervising physician). Participants comprised of seven black males and eight black females residing in Heilbron and neighbouring towns (Petrus Steyn and Edenville), in the Free-State. These participants were selected from the Tokollo District Hospital database. The data for the research were collected
by means of semi-structured interviews. The interviews took place between February and April 2017, based on the agreed upon date between the researcher and participants. Some of the participants requested to be interviewed at their respective homes, and a convenient date and time was set for the interviews to be conducted with those participants. The interviews were audio recorded, transcribed, and then inductive thematic content analysis was used to analyse the data (Braun & Clarke, 2006:87). The process consisted of firstly transcribing the recorded interviews, followed by a reading and re-reading process in order for the researcher to familiarise herself with the data and to generate initial insights in relation to the research question. With the research questions in mind, initial ideas were extracted from the transcribed interviews and were coded by means of descriptive labels that were assigned to these segments of text. The coding process was then followed by a subsequent phase where codes were examined for their similarities and differences and then grouped together into categories based on their conceptual similarities. In turn, the categories were grouped into overarching themes.

A total of eight main themes were identified from the analysed data in exploring flourishing among individuals diagnosed with HIV/AIDS. These included acceptance of the diagnosis, taking responsibility of condition, healthy living, faith and religious activities, social relationships, future orientation, motivating others, and music.

The findings of this study indicated that the first and biggest milestone to conquer was acceptance, in order to become proactive and face daily challenges. The participants in the study indicated that even though the diagnosis had a negative effect on their morale for some time after being diagnosed, accepting their diagnosis meant confronting being freed from the burden of stigma about the disease, and moving on with living a healthy and purposeful life, all of which supported them on the road towards flourishing. Bertolini et al. (2006) confirmed this by exclaiming that after diagnosis the psychological adaptation process begins in the diagnosed individual. Studies conducted also showed that when an illness is accepted it reduces a persistent emotional support from health professionals (Lyons, 2016:4). This finding was prevalent in the expressions of the different participants, as they conveyed their acceptance of the disease in a confident and positive manner. The participants also exclaimed that if they do not start by accepting themselves, then they cannot expect other people to accept them.
Following their acceptance of their condition, participants indicated that they now had to take responsibility of their condition and their general health. Responsibility meant that they are taking first steps towards making their health a priority by living healthily and practising safe sex. The participants indicated that taking responsibility also meant educating themselves, being aware of safety precautions, adopting a health promoting behaviour patterns and also preventing defaults that may occur as HIV/AIDS diagnosed individuals. Their views were that even though the government has a responsibility to provide adequate health facilities, individuals on the other hand have the responsibility to take care of their own health and have to work hard to maintain it; a point also made by Resnik (2007:445). To the participants, taking responsibility means regular exercising, a healthy diet, taking medication on schedule, and having a periodic medical check-up. Altogether, these lifestyle changes and behaviours emanating from a sense of responsibility played an important role in enabling the participants to flourish. The importance of these activities is supported in the context of existing literature (Bertolini et al., 2006:260). Such studies confirm that eating nutritious food and drinking water helps maintain energy, while exercising reduces stress, providing good night sleep as well as increasing appetite (WHO, 2002:2). This is to say, flourishing individuals no longer regarded themselves as passive victims to disease, but themselves participate in their recovery as well as the production of good health. The importance of such an attitude has also been noted by Gilbert et al. (1996:5).

The findings of the study also revealed that religious faith and activities were regarded as centrally important among participants in supporting their coping, optimism, and consequent flourishing. In line with this, previous researchers have also pointed out that beliefs and faith shape people’s behaviours, and inevitably affect health outcomes (Elliot & Dweck, 2005:6). Religious activities keep individuals grounded and also committed to their religion, promoting better and healthier behaviours resulting to positive outcomes like fewer intakes of harmful substances (alcohol and smoking). McCoullough et al. (2000) as cited in (Elliot & Dweck, 2005:24) maintained that highly religious people have a 29 percent higher likelihood of being alive at follow-up than less religious people. There are numerous positive health benefits of prayer and bible reading as reported by Sloan et al. (1998:341) as cited in Elliot & Dweck (2005:25) to increase hope to persist in the mist of hardships. In line with existing research, the results from this study showed that hardiness from HIV/AIDS flourishing individuals were associated significantly with religious activities like prayer, meditation, reading religious literature, and church attendance.
Moreover, the results from the study also indicated that social relationships play an important role in supporting HIV patients’ ability to flourish. Previous research confirms that social support enables individuals to cope with stress, by expressions of empathy and emotional venting. Performing a wide range of social activities to promote self-identity, purpose, self-worth, and positive affect have also been noted as other predictors of coping (Cohen, 2004:677). Interviewed participant often indicated that the support that they get from those they trust with the information about their diagnosis enabled them to engage more in activities that allowed them to be hopeful and very positive towards life.

Another factor found to contribute to flourishing among individuals diagnosed with HIV/AIDS is a future orientation. Participants in the study expressed that they generally were very hopeful of their future, and that, hope for a healthier future and attainment of their goals give them the ability to remain positive and flourish in spite of their diagnosis. Lens et al. (2012:327) expands on this by explaining that even though people live in the present, their lives incorporate elements from the past and an anticipated future, and that having a future orientation is a positive trait that supports well-being.

Furthermore, many participants indicated that they find meaning in helping to bring about positive change in the lives of individuals who have lost hope. Many stated that they wanted to serve as living examples of flourishing to others with HIV, and that this in itself contributed to their well-being. In line with this finding, Keyes (2002) indicates that activists are more likely to be flourishing than non-activists. This finding implies that there could be significant synergistic value in recruiting HIV positive individuals to work as counsellors as this is likely to be of great mutual benefit to both the counsellor (who derives meaning, purpose and fulfilment from helping others) and the counselee (who is provided with a role model of flourishing, and who is likely to be more receptive to what is said by someone in the same proverbial ‘boat’ than to an HIV negative counsellor).

Another finding from the study was that music often supported the well-being of individuals diagnosed with HIV. Music is therapeutic to those who listen to it, and is usually used to uplift people’s lives, by means of recalling pleasant and not so pleasant experiences from the past, present conditions, and a desired future (Kemper & Danhauer, 2005:284). The participants in the interviews indicated that when listening to music a sense of calm drives them to acknowledge and deal with present circumstances better. Also, listening to the lyrics
of the song motivates them to carry on. Music helps them to not over-think about their present situations, therefore, helping them focus on positivity and hope.

By outlining these factors that contribute to flourishing among individuals diagnosed with HIV/AIDS, the aims that were set for the study were fulfilled.

3.3 Implications

The findings that emerged from this study have a number of implications in relation to theory and practice. The implications of this study will be discussed in this section.

First, the study findings have a number of noteworthy implications for theory. In particular, it is hoped that the themes identified in this study will serve to contribute to the theoretical understanding of the antecedents of flourishing in the context of HIV/AIDS. In having outlined these factors associated with flourishing, it is further hoped that the findings will serve as a useful starting point for future research, which could be conducted with the aim of verifying and quantifying the contextually specific findings that emerged in this study.

Overall, the findings of the study suggest that the non-physical factors and strategies associated with flourishing far outnumber the bio-medical ones such as diet, exercise and taking of medication. As such, merely focusing on such matters, even if done successfully will be of limited use in supporting flourishing among HIV positive individuals. The findings imply that flourishing among such persons is likely to be promoted and sustained primarily (though certainly not exclusively) by explicitly addressing non bio-physical factors such as acceptance, religious faith, social support, goal setting etc.

Second, the findings also have a number of practical implications. In particular, it is hoped that the findings would be of use in informing the following:

- The development of interventions and programs aimed at enhancing or otherwise supporting the well-being of individuals diagnosed with HIV/AIDS;
- The training of both professional and lay HIV/AIDS counsellors, and by inference, the development and content of training material used to train such individuals;
- The activities of NGOs focusing on supporting HIV positive individuals.

In particular, the findings of the study suggest that in all the contexts outlined above, there would be value in emphasizing the importance of accepting the illness and promoting strategies aimed at enabling HIV positive individuals in reaching this point; emphasising self-
responsibility for the condition (and avoiding the inadvertent trap of preventing this from occurring by assuming responsibility on behalf of the diagnosed individual); emphasising the importance of a healthy lifestyle in terms of diet, exercise, adherence to medication regimens etc. and assisting patients in creating or findings structures to support them in these endeavours; drawing on the power of religious participants’ faith, and strengthening their connections with their religious communities as well as their social support networks in order to enhance support; and encouraging the beneficial use of music as active coping strategy. Given that these strategies are successfully utilised by HIV positive individuals, it seems likely that they will be context appropriate and suited to helping those diagnosed with the same condition who might be languishing or otherwise experiencing sub-optimal well-being. The fact that the participants involved in this study were able to flourish not only in the context of HIV, but also in the context of challenging socio-economic circumstances attest to the realistic value that these strategies might have in supporting others in similar circumstances. Most of these strategies do not require much in the line of financial input, and generally are readily available resources, which is a particularly important consideration when supporting HIV positive individuals who might live in impoverished communities.

Given that none of the strategies mentioned by the participants are uniquely relevant only to HIV/AIDS, it seems plausible that the findings of the present study might also be naturalistically generalized to HIV negative individuals who might be diagnosed with other chronic illnesses, and consequently could also be of value in informing the development of interventions, training material etc. associated with supporting those suffering from such conditions.

3.4 Limitations of the study

Although the research study answered the questions and fulfilled the aim of the research, jointly there were limitations. The interviewed participants in the study comprised of a comparatively small number of black males and females from rural and relatively impoverished communities near the Free State town of Heilbron. This suggests a primary barrier in transferring the research generally to diagnosed individuals across the country at large as well as to other racial and socio-economic groups. Therefore, additional research needs to take place to investigate whether the findings of this study would also apply in the context of other locations and demographic sub-groups.
3.5 Obstacles encountered

A number of obstacles were encountered during the course of the study. Firstly, there was an unexpected delay in committee decision making at the Department of Health in the Free-State, which caused a delay in commencing with the research. Secondly, unavoidable difficulties came about from locating and setting appointments with potential participants. Most participants requested to be interviewed at their homes, which meant travel costs increasing. Thirdly, after a scheduled appointment for interviews some potential participants would change dates due to personal matters. This resulted in a prolonging of the time required to complete the interviews, and caused the study to be completed later than planned. Fourthly, some participants were not very forthcoming during the initial interviews, and as such, data derived from these interviews were limited. To address this, follow up interviews were scheduled with these participants, which enabled the researcher to mitigate this obstacle.

3.6 Recommendations for future research

The findings of this research suggest that more research should be conducted with a larger sample and with people of different races and socio-economic groups, as well as different regions in South Africa. Whilst this was not the aim of the study, the specific processes and pathways through which the strategies used by participants facilitated their well-being has not been researched in depth in this study. For example, the findings of the study clearly suggest that acceptance of a diagnosis of HIV played a significant role in supporting participants’ capacity to flourish. However, the exact pathway or processes involved in this journey towards acceptance could provide a meaningful focus for future research. The same applies to the other strategies that were found in this study, such as religious faith and activities, social support, etc. It would be of value to understand the specific aspects and mechanisms involved in terms of how specifically these factors contribute to flourishing. As such, these aspect should be explored in future studies, and might prove to be of significant benefit in informing interventions, counsellor training programmes etc.

Future efforts and research could be directed at the development and testing of interventions (based on findings such as those derived from this study) to determine their effectiveness in enhancing flourishing among individuals diagnosed with HIV.
3.7 Personal reflections

In the context of qualitative research, which is informed by an interpretivistic epistemology, the researcher is not regarded as a neutral party, but is understood to be influential in the actual research process. As such, it is important for the researcher to conclude with a few notes outlining her own positioning vis-a-vis the study, and the subject which it addresses. I am a medical sociology Master’s Degree student at the North-West University, where I also completed my BA degree and Honours degree in Psychology. I’m an African woman from Heilbron in the Free-State, where I have been volunteering at the Tokollo Hospital since my Honours year, when I acted as facilitator for HIV positive women for my community psychology project. From that time, I noticed that HIV positive individuals are not vulnerable and demonstrably physically ‘sick’, but that most were actually very optimistic and hopeful for their future. I was then quite intrigued by this because, I also believed the stigma I read and heard about, of the disease being a death sentence. I was so amazed by the amount of persistence and the drive the HIV positive women demonstrated while conducting my sessions in my Honours years, I then developed the interest to know “how they do it”, which was the basic impulse prompting the present study, and the basis for entitling the mini-dissertation: “A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa.” Although I must confess that the long research process had its bad and good days, from the time of writing the proposal to the present time, and that there were days when my motivation sagged and I doubted whether I would finish, I drew strength to continue by always reminding myself of my passion of knowing how some HIV positive individuals live so positively. I was also buoyed up by interacting with the participants, and experiencing how open, positive and confident they were, which made me feel closer to what I had always wanted to find out. In the end, this journey has been extremely rewarding, and what I have discovered along the way has not only enabled me to answer my research questions, but has also enriched my life on a personal level.

3.8 Summary

This chapter provided a brief overview of the study, followed by a discussion of the conclusions and implications derived from the study. The limitations and obstacles of the study were then outlined. Furthermore, recommendations for future studies were also presented with the great hope that the factors that were outlined would support various
practical initiatives and interventions and that it would stimulate additional research and efforts aimed at empowering HIV/AIDS diagnosed individuals to flourish in their lives.
REFERENCES


file:///C:/Users/SesethuN/Downloads/HIVAIDS_and_nutrition_a_review.pdf Date of access: 10 Oct. 2017


APPENDIX A

From: Dr M. Mingi
Acting Clinical Manager
Tokollo/Mafube Complex

To: M.A. Research Student at North West University for Medical Sociology Masters Dissertation

Re: PERMISSION TO CONDUCT RESEARCH AUDITATIVE (EXPLORATIVE) RESEARCH FOR HIV POSITIVE PARTICIPANTS

Dear Sir/Madam

Tokollo/Mafube Complex District Hospital welcome your student Relebohile Lerato Tsotetsi 21474702 8906240298083 to conduct her research in our complex believing that this research will improve management of our patients. Note that your student must respect the confidentiality of our patients and ethical conduct of the complex.

Yours Faithfully

Dr M. Mingi
Acting Clinical Manager
Tokollo/Mafube Complex

Acknowledged

M. A. Makalema
Acting Chief Executive Officer
Tokollo/Mafube Complex
APPENDIX B

ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by the Humanities and Health Research Ethics Committee (HHREC) on 30/11/2016, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

**Project title:** A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS in South Africa.

**Project Leader/Supervisor:** Prof W Neil

**Student:** Ms L Tsotetsi

**Ethics number:** NWU-HS-2016-0150

**Application Type:** N/A

**Commencement date:** 2016-11-30

**Expiry date:** 2019-11-30

**Risk:** Medium

**Special conditions of the approval (if applicable):**
- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HHREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HHREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

**General conditions:**
While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:
- The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HHREC:
  - annually (or as otherwise requested) on the progress of the project, and upon completion of the project
  - without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project
- Annually a number of projects may be randomly selected for an external audit.
- The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the HHREC. Would there be deviations from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.
- The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-IRERC via HHREC and new approval received before or on the expiry date.
- In the interest of ethical responsibility the NWU-IRERC and HHREC retains the right to:
  - request access to any information or data at any time during the course of or after completion of the project;
  - to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;
  - withdraw or postpone approval if:
    - any unethical principles or practices of the project are revealed or suspected,
    - it becomes apparent that any relevant information was withheld from the HHREC or that information has been false or misrepresented,
    - the required annual report and reporting of adverse events was not done timely and accurately,
    - new institutional rules, national legislation or international conventions deem it necessary.
- HHREC can be contacted for further information via [contact details]

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the IRERC or HHREC for any further enquiries or requests for assistance.

Yours sincerely,

Linda du Plessis

Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)
APPENDIX C

5 December 2016

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR PARTICIPANTS

TITLE OF THE RESEARCH PROJECT: A qualitative exploration of flourishing among individuals diagnosed with HIV/AIDS

REFERENCE NUMBERS: NWU-HS-2016-0180

PRINCIPAL INVESTIGATOR: Relebohile Lerato Tsetetsi

ADDRESS: 1558 Khumalo street Heilbron Phiritona

CONTACT NUMBER: 07888571557

You are being invited to take part in a research project that forms part of my master’s mini-dissertation. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Humanities and Health Research Ethics Committee (HHREC) of the Faculty of Humanities of the North-West University (NWU-HS-2016-0180) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health

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Research Ethics Council. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records to make sure that we (the researchers) are conducting research in an ethical manner.

What is this research study all about?

- The goal of this research is to qualitatively explore flourishing (feeling good and functioning well) among individuals diagnosed with HIV/AIDS. Whereas previous studies tended to focus on the more problematic aspects of HIV/AIDS, the main focus on this study is on understanding how and why some people diagnosed with HIV/AIDS manage to be happy and function well (or flourish) in spite of their illness. To also understand if at all flourishing among individuals differs between females and males.

Why have you been invited to participate?

- You have been invited to participate because you have been diagnosed with HIV/AIDS and you are doing exceptionally well in your life as reflected by your CD4 count and the opinion of health-care professionals.
- You have also complied with the following inclusion criteria, in that you:
  - reside in the Free-state, especially Heilbron and the neighbouring towns,
  - are a patient at Tokollo hospital,
  - are 18 or older.
- You are not presently receiving any form of (psycho)therapy and you have not been diagnosed with any mental or emotional disorder.

What will your responsibilities be?

- You will be expected to answer the questions as truthfully as you can during the interview. There will be a series of two or three interviews (lasting more or less 30 minutes to one hour) in a period of one week to two weeks. You have the right to refuse to participate in the study or answer any questions you are uncomfortable with. Even if you consent to the first interview, you still have the right to refuse any additional interviews if you only wish to engage in a single interview. To make sure that the findings are reliable, you may be asked to provide feedback on the results of the data analysis.

Will you benefit from taking part in this research?

- Whilst talking about your own strengths and the ways in which you manage to flourish in spite of your illness might possibly be a positive experience for you, your participation will hold no direct benefits for you.
- The findings would be of theoretical interest to those who are involved in positive behavioural aspects of people diagnosed with HIV/AIDS. This will also help counsellors and health practitioners who aim to combat HIV/AIDS on a behavioural level. Moreover academics in the field of Sociology and Health will be interested in the outcomes of this research.

Are there risks involved in your taking part in this research and how will these be managed?

- It is not expected that your participation in this study will involve any significant risk. The research will not focus on the disease or sensitive matters that might make you...
uncomfortable, but rather on how and why you are doing and functioning so well in spite of your illness.

➢ As far as the researcher can state, it is unlikely that this study will produce any emotional distress, personal or cultural embarrassment, breach of confidentiality, economic harm, legal jeopardy, physical pain or injury to the participants, the researcher or gatekeeper. This is so as all that will be required of you is one to three 30-60 minute conversations (at a time and location convenient to you) about how you manage to function well. Should you feel that you get tired during the interview you are welcome to take a break for as long as you need.

➢ In the unlikely event that you should feel distressed as a result of the interview, counselling will be provided by the social worker at the hospital who will be on hand should the need for this arise.

Who will have access to the data?

➢ All information that might identify you as an individual will be kept safe in a secure room at the University and will not be available to others and will be kept confidential to the extent possible by law. The records on your participation may be reviewed by people responsible in making sure that the research is done properly, including my supervisor Dr Werner Nell and members of the North West University ethics committee. All the people mentioned here are required to keep your identity confidential. Otherwise, the records of your identification will only be available to people working with me on the study, unless you give permission for other people to see the records.

➢ I am asking for your permission to tape-record the interview so that I can record what we have talked about accurately.

➢ Your answers will be stored electronically in a very secure environment and will be used for research or academic purposes only now and maybe on a later date in ways that will still not reveal your identity. All future use of the stored data will be subject to further Research Ethics Committee review and approval.

➢ Unless you wish otherwise, I will not record your name anywhere in any place where the findings of this research is shared, and no one will be able to connect to the answers you will be providing here. Your name will be linked to a fictitious code (Participant 1) number and I will be referring to you like that in the data, any publication, report or other research output. The interviews should not take more than 1 hour.

➢ Data will be stored for 5 years in a locked cupboard in a private office.

What will happen to the data?
The data from this study will be reported in the following ways: The data will be used as part of a mini-dissertation. In all of this reporting, you will not be personally identified. This means that the reporting will not include your name or details that will help others to know that you participated (e.g., your address).

The data could be used in future studies for a purpose that is the same or very similar to that of the present study (exploring flourishing among individuals diagnosed with HIV/AIDS), but will not be used for any other purpose/s than this.

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Will you be paid/compensated to take part in this study and are there any costs involved?

No you will not be paid/compensated to take part in the study, but light refreshments will be provided.

How will you know about the findings?

➢ The general findings of the research will be shared with you by the researcher if you want to know what the findings were.

Is there anything else that you should know or do?

➢ You can contact the researcher, Relebohile Lerato Tsetse, at 0788571557 if you have any further queries or if you encounter any problems.
➢ You can contact the chair of the Humanities and Health Research Ethics Committee Prof Tumi Khumalo (016 910 3397 or Tumi.khumalo@nwu.ac.za) if you have any concerns or complaints that have not been adequately addressed by the researcher.
➢ You can leave a message for Tumi with Ms Daleen Claassens (016 910 30441)
➢ You will receive a copy of this information and consent form for your own records.
Declaration by participant

By signing below, I ............................................................ agree to take part in a research study entitled:

I declare that:

- I have read and understood this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions to both the person obtaining consent, as well as the researcher (if this is a different person), and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I understand that what I contribute (what I report/say) could be reproduced publically and/or quoted, but without reference to my personal identity.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (place) ......................................................... on (date) .............................. 20...

.................................................................................................................................  .................................................................
Signature of participant                                              Signature of witness

- You may contact me again
- I would like a summary of the findings of this research

☐ Yes ☐ No

☐ Yes ☐ No

The best way to reach me is:

Name & Surname: ____________________________________________________________
Postal Address: ____________________________________________________________
Email: ________________________________
Phone Number: ____________________________
Cell Phone Number: ____________________________

In case the above details change, please contact the following person who knows me well and who does not live with me and who will help you to contact me:

Name & Surname: ____________________________________________________________

Phone/Cell Phone Number/Email: ____________________________________________

5

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Declaration by person obtaining consent

I (name) .............................................................. declare that:

- I explained the information in this document to ..............................................
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter.

Signed at (place) .............................................. on (date) ......................... 20...

_________________________________________  ____________________________
Signature of person obtaining consent     Signature of witness

Declaration by researcher

I (name) .............................................................. declare that:

- I explained the information in this document to ..............................................
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter.

Signed at (place) .............................................. on (date) ......................... 20...

_________________________________________  ____________________________
Signature of researcher                   Signature of witness

This document is an adapted version of the one used by HREC, Potchefstroom Campus (HREC General WICF Version 2, August 2014).