Growing old with HIV: narratives of women in Manicaland, Zimbabwe

by

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DECLARATION

I hereby declare that this dissertation submitted in completion of the Master’s degree in Arts (Sociology) at the University of the Free State is my own original work and has not been submitted previously at another institution, faculty or department.

I further concede copyright of this dissertation to the University of the Free State.

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December 2016
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• The University of the Free State Postgraduate School
• The person who edited the dissertation
• The person who translated the summary to Afrikaans
• My family
DEDICATION

I dedicate this work to my mother who inspires my interest into HIV and AIDS issues. She is a champion in many ways.
## CONTENTS TABLE

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>DECLARATION</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>ii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>iii</td>
</tr>
<tr>
<td>CONTENTS TABLE</td>
<td>iv</td>
</tr>
<tr>
<td>TABLE OF FIGURES</td>
<td>viii</td>
</tr>
<tr>
<td>SUMMARY</td>
<td>ix</td>
</tr>
<tr>
<td>OPSOMMING</td>
<td>xii</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>CHAPTER 1 — THEORETICAL FRAMEWORK</td>
<td>6</td>
</tr>
<tr>
<td>1.1 The interpretive framework</td>
<td>7</td>
</tr>
<tr>
<td>1.2 Phenomenology</td>
<td>9</td>
</tr>
<tr>
<td>1.2.1 The lifeworld</td>
<td>10</td>
</tr>
<tr>
<td>1.2.1.1 The lifeworld influenced by culture</td>
<td>11</td>
</tr>
<tr>
<td>1.2.1.2 The lifeworld of an ageing body</td>
<td>13</td>
</tr>
<tr>
<td>1.2.1.3 Typifications in the lifeworld</td>
<td>17</td>
</tr>
<tr>
<td>1.2.2 Lived experiences of women who are growing old with HIV</td>
<td>20</td>
</tr>
<tr>
<td>1.2.3 Intersubjectivity</td>
<td>21</td>
</tr>
<tr>
<td>1.2.4 Consciousness</td>
<td>22</td>
</tr>
<tr>
<td>1.3 The social construction of reality</td>
<td>24</td>
</tr>
<tr>
<td>1.3.1 The social construction of age and HIV</td>
<td>27</td>
</tr>
<tr>
<td>1.3.2 Creating meaning</td>
<td>28</td>
</tr>
<tr>
<td>1.4 Existential phenomenology</td>
<td>31</td>
</tr>
<tr>
<td>1.5 A gender framework in relation to older women with HIV</td>
<td>33</td>
</tr>
<tr>
<td>CHAPTER 2 — LITERATURE REVIEW</td>
<td>37</td>
</tr>
<tr>
<td>2.1 The Human Immunodeficiency Virus (HIV) prevalence</td>
<td>38</td>
</tr>
</tbody>
</table>
2.2 HIV and ageing in women ................................................................. 38
2.3 HIV and the lifeworld of a woman who is growing old with HIV ............. 40
2.4 Social construction of reality and stigma ............................................ 41
  2.4.1 How HIV and age can be socially constructed ................................. 44
  2.4.2 Creating new meanings as people grow old with HIV ..................... 47
2.5 Typifications in the life of a person who is growing old with HIV ............. 49
2.6 Lived experiences of older women with HIV ...................................... 53
  2.6.1 Social life in older people .............................................................. 54
  2.6.2 HIV and the family ........................................................................ 55
  2.6.3 The physiological needs of older women with HIV ......................... 57
  2.6.4 Social roles and everyday activities ............................................... 58
2.7 Intersubjectivity and disclosure of HIV status ...................................... 60
2.8 Existential phenomenological experiences of older women with HIV ....... 62
  2.8.1 Coping with HIV .......................................................................... 63
    2.8.1.1 Social support ........................................................................... 64
    2.8.1.2 Religion .................................................................................... 64
    2.8.1.3 Hope and optimism ................................................................. 65
    2.8.1.4 Accepting being HIV-positive ................................................ 65
    2.8.1.5 Mal-adaptive coping ............................................................... 66
2.9 Gender and the experiences of older women with HIV ......................... 67
  2.9.1 Gender inequality and HIV vulnerability ........................................ 67
  2.9.2 Marriage and HIV ......................................................................... 70
  2.9.3 Women and HIV-related stereotypes ............................................ 72

CHAPTER 3 — METHODOLOGICAL ACCOUNT ......................................... 74
3.1 Research design ................................................................................... 74
3.2 Situating my study within the philosophical and theoretical paradigms that underpin qualitative inquiry ......................................................... 75
3.3 Aim and objectives of the study .......................................................... 77
3.4 Research questions .............................................................................................................. 78
3.5 Research area ......................................................................................................................... 78
3.6 Selecting the research participants ......................................................................................... 80
3.7 Pilot study .............................................................................................................................. 82
3.8 Rapport between interviewer and interviewees ...................................................................... 83
3.9 Data collection ....................................................................................................................... 84
3.10 Data analysis ......................................................................................................................... 87
3.11 Credibility and trustworthiness ............................................................................................ 90
3.12 Ethical considerations ........................................................................................................... 92
  3.12.1 Permission to conduct research ....................................................................................... 92
  3.12.2 Informed consent ............................................................................................................. 92
  3.12.3 Mitigation of risks ............................................................................................................ 93
  3.12.4 Confidentiality ................................................................................................................ 94
  3.12.5 Appreciation of participants ........................................................................................... 95
  3.12.6 Exiting the research field ............................................................................................... 95

CHAPTER 4 — DATA ANALYSIS ................................................................................................. 97
4.1 Pre-diagnosis experiences .................................................................................................... 99
4.2 Post diagnosis experiences ................................................................................................ 109
4.3 Adapting and adjusting to the condition ............................................................................. 123
  4.3.1 Understanding the condition ......................................................................................... 124
  4.3.2 Accepting the condition ................................................................................................. 129
  4.3.3 Managing the condition ................................................................................................ 132
4.4 Life in the future .................................................................................................................. 147
4.5 These women say, “It is very different for men.” ................................................................ 150

CHAPTER 5 — CONCLUSION .................................................................................................... 154
5.1 Pre-diagnosis experiences .................................................................................................. 154
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1.1 Marriage secures a woman’s life</td>
<td>156</td>
</tr>
<tr>
<td>5.1.2 HIV equals frailty</td>
<td>157</td>
</tr>
<tr>
<td>5.1.3 The more HIV is hidden, the better</td>
<td>158</td>
</tr>
<tr>
<td>5.1.4 The beginning of HIV is the end of everything</td>
<td>158</td>
</tr>
<tr>
<td>5.1.5 HIV infection is determined by age</td>
<td>159</td>
</tr>
<tr>
<td>5.2 Post diagnosis experiences</td>
<td>160</td>
</tr>
<tr>
<td>5.2.1 Emotional distress</td>
<td>161</td>
</tr>
<tr>
<td>5.2.2 Self-pity</td>
<td>161</td>
</tr>
<tr>
<td>5.2.3 Disclosure of HIV-positive status</td>
<td>162</td>
</tr>
<tr>
<td>5.2.4 Stigma and discrimination</td>
<td>162</td>
</tr>
<tr>
<td>5.2.5 Consciousness</td>
<td>164</td>
</tr>
<tr>
<td>5.3 Adapting and adjusting to the condition</td>
<td>165</td>
</tr>
<tr>
<td>5.3.1 Understanding the condition</td>
<td>165</td>
</tr>
<tr>
<td>5.3.2 Accepting the condition</td>
<td>166</td>
</tr>
<tr>
<td>5.3.3 Managing the condition</td>
<td>166</td>
</tr>
<tr>
<td>5.4 Life in the future</td>
<td>168</td>
</tr>
<tr>
<td>5.5 Gendered experiences</td>
<td>169</td>
</tr>
<tr>
<td>5.6 Limitations of the study</td>
<td>171</td>
</tr>
<tr>
<td>5.7 Value of the research and implications for future study</td>
<td>172</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>173</td>
</tr>
<tr>
<td>APPENDIX 1 — ETHICAL CLEARANCE (UFS)</td>
<td>193</td>
</tr>
<tr>
<td>APPENDIX 2 — ETHICAL CLEARANCE (MRCZ)</td>
<td>194</td>
</tr>
<tr>
<td>APPENDIX 3 — INFORMATION SHEET</td>
<td>195</td>
</tr>
<tr>
<td>APPENDIX 4 — CONSENT FORM</td>
<td>197</td>
</tr>
<tr>
<td>APPENDIX 5 — INTERVIEW GUIDE</td>
<td>201</td>
</tr>
</tbody>
</table>
**TABLE OF FIGURES**

- Fig.1: Consciousness and meaning-making model .................................................. 30
- Fig.2: Research area ...................................................................................................... 79
- Fig.3: Key themes .......................................................................................................... 98
SUMMARY

In this study, research participants’ narratives provide knowledge and a better understanding of the nature of life of women who are living and growing old with HIV. I use phenomenology as a principal lens to study the research participants’ lived experiences, social realities, existential being, and gendered lives. Phenomenological assumptions inform us that experiences are subjectively (personally), intersubjectively (interpersonally) and objectively (culturally and historically) impacted upon by different realities that exist in society.

This study is interpretive — research participants share their unique perspectives. As a result, I adopt a qualitative approach to obtain the research participants’ first-hand narratives about their life stories. Audio-recorded, semi-structured and in-depth interviews with eight purposively-selected women, aged fifty to sixty-five years and living in the Manicaland Province of Zimbabwe, were conducted. Informed consent from the participants was obtained after approval to conduct the research by the Medical Research Council of Zimbabwe and the Ethical Committee of the University of the Free State’s Faculty of the Humanities. A thematic data analysis approach was used to make sense of the data gathered. The process yielded various themes and eventually produced four major over-arching themes, which are pre-diagnosis experiences, post-diagnosis experiences, adapting and adjusting to the condition, and life in the future. These phases are congruent with the notion that lived experiences are temporal, organised and inform each other. In addition, the analyses are also organised with reference to the observations that people who suffer from chronic conditions initially undergo a phase of inner struggle with regard to the reality of living with that condition, but come to terms with that reality over time and undertake to live positively with it.
The ordinary everyday life experiences are mainly intersubjective, with people aligning their thoughts, judgements and actions with the common and shared knowledge and assumptions that construct and order life in that society. As noted in the findings, the research participants were initially not knowledgeable, some were fatalistic of the existence of HIV in their lives and others took long to implement proper courses of action to manage their condition. Consequently, their perspectives on HIV were mainly guided by the socially constructed assumptions and misconceptions about HIV existing in their communities. Some report that they encountered great difficulties during the disclosure of their HIV-positive status to those they deemed fit or trusted. Later on, proper support and age-influenced maturity assisted the research participants to acquire competencies that enabled them to deal with HIV in a positive way. They eventually adjusted and adapted well as they made efforts to understand, accept and manage their condition in a way that facilitates the re(creation) of the social order.

The development of functional new meanings, such as a positive outlook on life, positive perception of self and personal strength, result in a positive outlook of the future, where some research participants hope for an HIV cure in their lifetime. Others, less ambitiously, hope to get well enough to return to their old activities such as engaging in cross-border businesses. They also acquired the ability to assess the impact of societal norms, beliefs and practices on their condition and discern what works for them, rather than acting blindly according to what is socially-accepted. Nevertheless, despite these positives, the research participants still have concerns about what lies ahead as they worry about the unpredictable effects of HIV and old age.

The participants’ experiences as women, are also impacted by societal norms and values that relegate them to an inferior position in heterosexual relationships. Gender imbalances and
inequality disempower women with regard to taking relevant courses of action to prevent or alleviate the effects of HIV owing to the societal expectations that women be submissive on issues that involve sexuality and the conduct of their husbands. Most of the research participants acknowledge that their experiences in this life-changing condition (HIV-positive) were complicated by their upholding of societal norms instead of having a greater regard for their personal wellbeing.

On the whole, the study observes that the research participants create new meanings to live well with HIV despite the existing challenging social structures in their society.
In hierdie studie verskaf die vertellings van navorsingsdeelnemers ‘n beter begrip van die lewens van vrouens wat met MIV oud word. Ek gebruik die fenomenologie as hooflens om die deelnemers se ervarings, sosiale realiteit, eksistensiële wese, en lewe as vrouens te bestudeer. Fenomenologiese aannames leer ons dat ervarings subjektief (persoonlik), intersubjektief (interpersoonlik) en objektief (kultureel en histories) geimpakteer word deur verskeie samelewingsrealiteite.

Die studie is interpretatief – waarin navorsingsdeelnemers hul unieke perspektiewe deel. Om hierdie rede het ek ‘n kwalitatiewe benadering gevolg om eerstehandse vertellings oor die deelnemers se lewensverhale in te win. Semi-gestruktureerde, in-diepte onderhoude (wat digital opgeneem is), is met met doelgerig-geselekteerde vroue, tussen die ouderdomme van vyftig tot vyf-en-sestig jaar (wat in Manicaland, Zimbabwe, woon), gevoer. Hierdie onderhoude is met hulle ingeligte toestemming uitgevoer, nadat daar goedkeuring verky is van die Mediese Navorsingsraad van Zimbabwe sowel as die Etiese Komitee van die Fakulteit Geesteswetenskappe (Universiteit van die Vrystaat). ‘n Tematische data-analise benadering is gebruik om sin te maak van die ingesamelde data. Die proses het verskeie temas opgelewer wat uiteindelik in vier hoof oorkoopende temas saamgevat kan word: pre-diagnose ervarings, post-diagnose ervarings, aanpassing tot die toestand, en die lewe in die toekoms. Hierdie fases is kongruent met die idee dat ervarings tydelik is, georganiseer is en ook met mekaar ineenskakel. In aansluiting hiermee is die analise georganiseer in terme van die observasie dat individue wat aan ‘n kroniese toestand ly, aanvanklik ‘n tydperk van wroeging deurmaak, voordat hulle die werklikheid van die toestand aanvaar en leer en onderneem om op ‘n positiewe wyse met die toestand saam te leef.
Alledaagse ervarings is hoofsaaklik intersubjektief, waar mense hulle gedagtes, oordele en gedrag in lyn bring met gemeenskaplike en gedeelde kennis en aannames wat die lewe in hulle samelewing konstrueer en orden. Soos in die bevindinge gemeld, was hierdie vroue aanvanklik nie bewus van die bestaan van MIV in hul lewens nie, en het dit lank geneem om behoorlike aksieplanne in werking te stel om hulle toestand te bestuur. As gevolg hiervan, is hul siening van MIV hoofsaaklik geleidelik beïnvloed deur die sosiaal gekonstrueerde aannames en wanopvatting oor MIV wat in hulle gemeenskappe bestaan. Hulle het met moeite hulle MIV-positiewe status met diegene wat hulle “vertrouelinge” geag het, gedeel. Mettertyd het behoorlike ondersteuning en ouderdom beïnvloed volwassenheid die deelnemers instaag gestel om vaardighede aan te leer wat hulle gehelp het om MIV op ‘n positiewe wyse te hanteer. Hulle het later aangepas en pogings aangewend om hulle toestand te verstaan, te aanvaar en te bestuur op ‘n wyse wat die skepping van sosiale orde fasliteer.

Die ontwikkeling van funksionele nuwe betekenisse, soos ‘n positiewe uitkyk op die lewe, positiewe selfpersepsie en persoonlike krag, geleli tot ‘n positiewe uitkyk op die toekoms waar sommige deelnemers hoop op ‘n MIV-kuur in hul leeftyd en ander, minder ambisieus, hoop om gesond genoeg te word sodat hulle terug kan keer na hulle besighede. Hulle het ook die vermoë aangeleer om die impak van samelewingsnorme, oortuigings en praktyke op hul toestand te evalueer en om aan te neem wat vir hulle werk, eerder as om blindelings op te tree volgens wat sosiaal aanvaarbaar is. Ten spyte van hierdie positiewe aspekte, is die deelnemers tog bekommerd oor die onvoorspelbare gevolge van MIV en ouderdom.

Die ervarings van die deelnemers as vrouens, is ook beïnvloed deur die samelewingsnorme en waardes wat aan vrouens ‘n onderdaninge posisie in heteroseksuele verhoudings toesê. Die geslagswanbalanse en ongelykheid ontmagtig vroue om toepaslike aksies te neem om MIV te
vermy of die effek daarvan te verlig aangesien hulle gebind word deur samelewingsverwagtings wat verwag dat hulle ondaning moet wees in kwessies wat seksualiteit en die gedrag van hulle mans aanbetref. Die meeste deelnemers erken dat hulle hulself in hierdie posisie (MIV-positief) bevind omdat hulle samelewingsnorme belangriker as persoonlik welstand geag het.

In die geheel gesien, soos wat die deelnemers ouer met MIV word, skep hulle nuwe betekenisse om goeie/volle lewens te lei met MIV ten spyte van uitdagende sosiale strukture binne hulle samelewing.
INTRODUCTION

This interpretative study examines the narratives of women who are growing old with HIV in the Manicaland Province of Zimbabwe in an effort to understand their experiences. The principal theoretical lens used to explore their experiences is phenomenology, which entails the study of people’s worldly engagements as active agents in the social world and concerned with making sense of their everyday experiences. As such, a more nuanced understanding and knowledge of the research participants’ experiences and nature of their reality is achieved using the philosophical principles of ontology and epistemology. The following questions guide this research:

- How do women create meaning of their everyday experiences as they negotiate living with HIV whilst ageing?

- To what extent does society’s portrayal of HIV influence the subjective thoughts and actions of research participants especially in terms of how they deal with stigmas attached to HIV?

- Which specific issues emerge from the women’s experiences of ageing with HIV?

The study considers the way HIV impacts on the women’s bodies and their social lives. Women who are growing old with HIV have to contend with the negative impact of HIV on the body and other social challenges such as values, norms, networks, structures and traditions that regulate behaviour, interactions, thoughts and actions (Mbonu, van den Borne & De Vries 2009: 1; Auerbach, Parkhurst & Cáceres 2011: S294). One of this research finding is that the

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1 HIV stands for The Human Immunodeficiency Virus

2 Ontology is the philosophical study of how things are, such as the nature of reality.

3 Epistemology concerns knowledge or how we know things, such as the knowledge of reality.
research participants fell victim to an HIV infection because of their status as women whose conduct is regulated by patriarchal norms that award them an inferior social status. Thus, societal norms have an impact on how meanings are created in the everyday life of these research participants.

The women, whose physical being is under threat from a chronic medical condition in a context where that condition is socially constructed as undesirable, exhibited some psychological distress as their initial reaction to the diagnosis of HIV. Societal precepts regarding HIV, where HIV is recognised as a despised condition, distressed the research participants because they viewed this as turning them into societal misfits. Even the way they responded to situations initially, for instance delaying the disclosure of their HIV status, was influenced by the commonly shared assumptions and perceptions towards HIV as they wanted to maintain their social fitting in the community. This is revealed through ways such as the women’s execution of their wifely roles in accordance with the socially expected conduct of a woman in their community. For example, the women did not rebuke husbands who were engaging in risky sexual encounters because, as is the norm in their patriarchal society, they felt too inferior to question their husbands’ sexual behaviours. They also did not take constructive courses of action to prevent HIV, such as going for HIV testing, because they blindly assumed that HIV can be detected by physical looks, and they looked healthy.

Theory proposes that lived experiences are temporal and things occur sequentially (Rogers 1983: 37). Thus, the experiences of people who live with a chronic condition such as HIV are believed to follow a transformation process where they are initially devastated by the effects of that condition (both social and physical) and later on adopt ways that enable them to take control of their lives and constitute satisfying social interactions (Tsarenko and Polonsky 2011:
This is confirmed in this research where, as the research participants grow older, they adopt competencies to live well with HIV, irrespective of how society discredits it, and overcame the existential discomforts related to their condition.

The research participants reached a stage where they became less concerned with the negative perceptions and reactions (stigma and discrimination) towards them. They began to put their health first before tradition, shared assumptions and various normative demands that organise life in their society but do not fit the demands of living healthily with HIV. Their view of the future is also positive owing to the belief that their satisfactory present circumstance, after enduring tough challenges in the past, can only lead to an optimistic future. Rogers (1983: 38) maintains that past experiences prescribe and shape future expectations because “every experience is future-oriented”. Hence, the participants’ past and present experiences form a relatively stable background for them to live meaningfully, and adapt in the years to come.

The study draws on the narratives of a selected eight women. Their narrations are categorised into four phases of experience: how life was before an HIV diagnosis, how life was after diagnosis, how they adapted and adjusted to their condition and how life will be in the coming years. The research participants’ experience are juxtaposed in all these phases, with the social, physical and bio-medical aspects of living with HIV as an older woman, as derived from a review of existing literature on the topic.

The study is structured as follows:
Chapter 1 outlines the theoretical frameworks underpinning this study. It presents phenomenology, social construction of reality, existential phenomenology and gender as the theoretical lenses for exploring the experiences of the research participants.

Chapter 2 reviews the scholarly literature focusing on HIV and ageing in order to understand better the phenomenon under study. The review brings together essential epidemiological and bio-medical information on HIV with other significant ideas concerning the lifeworld, such as social context, typifications, intersubjectivity constituted realities, consciousness, and gender issues as they relate to HIV and ageing.

Chapter 3 describes the study’s methodology. It focuses on the research design, philosophical and theoretical paradigms guiding the research method, aim and objectives of the study and the research questions. I also describe, in this chapter, the background of the research participants, how they were selected, the preliminary arrangements used to foster a good relationship with them, the data gathering methods, pilot study and the actual process of data collection. Following this, a summary of how data were analysed is outlined. Lastly, the chapter outlines aspects on the credibility and trustworthiness of the research processes and quality of data, as well as the ethical considerations of the research.

Chapter 4 presents the findings from the analyses of interview data. It incorporates discussions that link the findings to the relevant theoretical aspects and reviewed literature. The study findings are presented according to the over-arching themes of pre-diagnosis experiences, post-diagnosis experiences, adjusting and adapting to the condition, and life in the future. The chapter also offers a gender-related theme in relation to the way the findings portray the women’s experiences as different from men.
Chapter 5 presents conclusions in line with the major over-arching themes formulated during data analysis. These conclusions are therefore based on the findings relating to pre-diagnosis experiences, post-diagnosis experiences, adapting and adjusting to the condition, life in the future, and gender. The chapter concludes with a discussion on the limitations, value and implications of the study.
CHAPTER 1 — THEORETICAL FRAMEWORK

This study highlights how a group of ageing women deal with the reality of living with HIV. It explores their everyday experiences using interpretive sociology as an overall theoretical framework in which research participants interpret their experiences in relation to their social world. It also presents phenomenology as a theoretical lens for exploring the experiences of the research participants. Particular focus is given to the views of Alfred Schutz, where the interplay between agency (the active individual) and structure (factors of social influence) are analysed in order to understand how perspectives are subjectively constituted in everyday life.

This chapter also draws on Peter Berger and Thomas Luckmann’s ideas on the social construction of reality as it explores the research participants’ reality and how they orient their lives within the context of HIV, their society’s demands and within the context of their changing bodies. In addition, the chapter considers the link between HIV and the emotions of those who are infected and affected. As such, aspects of existential phenomenology are used to unlock their feelings and emotions as people who are in the process of ageing with HIV. Lastly, gender theories add further to the theoretical context of this project focusing on the ways that the research participants’ experiences are influenced by their status as women. Thus, this research is guided by phenomenology, the social construction of reality, existential phenomenology and gender theories.
1.1 The interpretive framework

The main focus of this study is to understand the phenomenon of growing old with HIV through the perspectives and experiences of the research participants. It is a primary aim of sociology to understand everyday life (Douglas 1971: 3) and, to a greater extent, unwrap meanings and motives that underpin human behaviour (Coetzee & Rau 2009: 1). Equally, a hermeneutic enquiry, which guides my data collection, involves a process of bringing out what is normally hidden in human experiences and relations (Lopez & Willis 2004: 728). I therefore use the research participants’ narratives to understand their everyday life and the meanings they attach to their experiences.

The main goal of an interpretive approach is to understand a phenomenon from the perspectives of individuals who are actively constructing meaning (Hitzler 2005: 3) of their unique individual experiences. This can be achieved by obtaining first-hand accounts of everyday life from the people involved, and as interpreted by themselves (Josselson & Lieblich 1995: ix). In this case, those who are growing old with HIV are the best positioned to describe the nature of life under such conditions. Thus, the research participants’ narratives provide a better understanding of their lived everyday experiences since researchers work with, as Josselson and Lieblich (1995: ix) put it, “what is said and what is not said, within the context in which life is lived and the context of the interview in which words are spoken to represent that life.” Accordingly, the research participants’ experiences are interpreted primarily from what they disclose from their collection of remembered events to the interviewer.

The ontological point of departure for this research, therefore, is that reality can be understood and interpreted through the narratives of women who are growing old with HIV. They are the
most suitable people to describe stories of their everyday life experiences and how they attach meaning (actions, emotions and perceptions) to events and experiences (Overgaard & Zahavi 2009: 93). As Peter Berger and Thomas Luckmann (1966: 20) argue, the world of everyday life originates in the thoughts of the people concerned. Jon Hendricks, in writing on ageing in general, states that no one can understand how meaning is constructed in a person’s life unless that person’s interpretation of events is appreciated (Hendricks 1999: 197). The qualitative methodology used in this study allows for the study of meaning because it involves conversational in-depth interviews with room for further probing for rich data. I rely as much as possible on the participants’ personal interpretation and reflection on everyday life since their world is best understood by themselves and the uniqueness of meanings of their experiences is best brought out by them.

Furthermore, the fact that people are able to constitute meaning, often in a unique manner, indicates that they interpret social realities in this shared social world differently. Interpretative sociology allows for different interpretations of realities to be revealed through individuals’ interpretation of their experiences (Creswell 2013: 20). As one of the founding figures of the discipline of sociology, Max Weber (1864-1920), with his emphasis on understanding purposes and meanings of social actions (Verstehen), points out that the goal of interpretive sociology is to interpret human actions in the social world and the subjective meanings they offer to a social phenomenon (Schutz 1967: 6). Edmund Husserl (1859-1938), another classical phenomenological theorist, shares the same sentiments as shown in the statement that the starting point of an inquiry must be what is given to the researcher by the people under study (Bello 2010: 287). This must be taken and understood as given without prejudice but, without disregarding the researcher’s personal interpretation of the theory of reality (Bello 2010: 287). It is the researcher’s theoretical framework that guides and gives focus to the whole enquiry
Accordingly, this study aims to gain a better understanding of the fundamental nature of living with life-threatening conditions, such as HIV and ageing, through the research participants’ narratives and within the theoretical frameworks discussed in the following sub-sections.

1.2 Phenomenology

A phenomenological approach is applied in this study as a specific lens within the interpretive framework to explore the research participants’ experiences through philosophical descriptions as highlighted by Sokolowski (2000: 87). In its most basic form, phenomenology seeks to understand the existence of a set of things in relation to a particular line of thought or theory (Bello 2010: 288). Its principal aim is to understand the nature or meaning of people’s everyday experiences (Van Manen 1990: 9). In view of this, phenomenology tries to explain human nature through the analysis of a person’s intentions and experiences. Therefore, I use phenomenology in this study to seek knowledge (epistemology) about the lived experiences of women who are living with HIV into an advanced age.

Edmund Husserl (1859-1938), the founder of phenomenology, was interested in investigating how a human mind works in creating sense of the things in the world (Inglis & Thorpe 2012: 87). However, it was Alfred Schutz (1899-1959), who developed the phenomenological paradigm further by focusing more on how subjectivity, intersubjectivity and objectivity impact on human action (Schutz 1967: (xv). Alfred Schutz emphasises the analysis of agency and structure in the lived experiences of everyday life. Agency is encapsulated in the active everyday person with practical interests that are influenced by common sense knowledge and understanding (Overgaard & Zahavi 2009: 100). Structure refers to “networks of recurring
patterns in which people behave in routine situations” (Berger & Berger 1975: 6). Therefore, in an attempt to understand and gain knowledge about the experiences of research participants, I focus on agency and structure to determine how experiences are objectively, subjectively and intersubjectively influenced.

The aim of this research project is to understand the everyday life of people through, what Inglis and Thorpe (2012: 86) term, their perceptions and conceptions of what surrounds them and how they engage with their surroundings. Hence, emphasis is put on incidences that are observable (Inglis & Thorpe 2012: 86), incidences that are directed by consciousness, motives and understanding of the everyday life (Overgaard & Zahavi 2009: 101) and also incidences that are recorded in the memory of research participants. These concepts underpin this research. I discuss aspects related to phenomenological analysis in the following subsections.

### 1.2.1 The lifeworld

Edmund Husserl (1859-1938) terms the world of natural attitude, the lifeworld, because it is the world that is given to people in their immediate experience (Lebenswelt) (Gurwitsch 1962: 51). Alfred Schutz (1899-1959) takes the concept lifeworld and analyses it further. He describes the lifeworld as the ordinary everyday world in which people operate (Inglis & Thorpe 2012: 90). The Schutzian view on the lifeworld points to the fact that the lifeworld is the background against which everyday thinking and acting take place (Flick, Kardorff & Steinke 2004: 67). Hence, every thought and act is influenced by the situation that one is operating in since the lifeworld is the fundamental overall reality within which an individual’s life is lived (Schutz & Luckmann 1973: 35).
Activities in the lifeworld are mostly ordinary, unnoticed, taken for granted and often not thought about or questioned (Schutz & Luckmann 1973: 4; Jacobsen 2009: 1; Overgaard & Zahavi 2009: 97). There however, exist limitations and barriers for free action, as the lifeworld is shared with other people who often hold different perceptions and consciousness and because of the fact that one’s lifeworld is part of the broader socially constructed world of everyday reality (Schutz & Luckmann 1973:4). Accordingly, the world of everyday life is a world that is not private but common to everyone with a practical interest in it (Gurwitsch 1962: 52; Holzner 1972: 2). In the following subsections, I discuss some of the social and biological facts that form the background for everyday thoughts and actions of, as well as the limitations and barriers to, women who are ageing with HIV.

1.2.1.1 The lifeworld influenced by culture

The lifeworld involves, as well, life as lived in line with people’s beliefs and cultural practices (Jacobsen 2009: 12). George Ritzer (2012: 539) asserts that the lifeworld has three main components, which are, culture, society and personality. He argues further that culture forms the background for assumptions about action, social relations and people’s personality (Ritzer 2012: 539). Therefore, there is cultural reproduction, social integration and personality formulation in the lifeworld (Ritzer 2012: 539). In line with the same view, Inglis and Thorpe (2012: 90) maintain that culture forms or influences the lifeworld in which things are mainly done and experienced through common sense. Hence, research participants’ experiences are explored to ascertain how culture influences everyday practices.

A close examination of Mazrui’s (1986: 239) definition of culture shows that it is “a system of interrelated values active enough to influence and condition perception, judgment,
communication, and behaviour in a given society.” Society is considered as people’s experience with others and serves as the context of experience of others, ourselves and the natural world as a whole (Berger & Berger 1975: 3). This view supports Inglis and Thorpe’s (2012: 89) position that culture defines a society and forms the context of all actions, interactions and ways in which one experiences the world. Research participants live in an established and culturally contextualised lifeworld which has its own culturally defined ways of dealing with ageing and HIV. Furthermore, Airhihenbuwa and Webster’s (2004: 5) view that African beliefs and values impact significantly on a person’s health behaviour, can bring an understanding to the meanings that research participants assign to aspects like roles, sexuality, stigma, sickness, healing and specifically HIV.

Alfred Schutz finds no problem in orienting actions to suit the demands of a situation or occurrence that is regarded as a problem or crisis (Schutz & Luckmann 1973: 21). He describes it as a natural attitude — “the attitude of the world of everyday life” that is determined by a rational motive (Schutz & Luckmann 1973: 6; Hughes & Sharrock 1980: 1). What is often regarded as a natural mode in this case, may be reflected upon philosophically and altered by actions that appear rational and sensible within the demands of a problematic situation. In the context of this research, people may disregard the demands of culture, such as handling the sick, and rather choose to apply the recommended scientific measures to avoid HIV transmission.

The management of HIV has its own scientific demands which dictate how to avoid the transmission of the virus upon exposure. Such scientific regulations can clash with the cultural ways that society recognise as appropriate in handling a person who is not well. For example, the Zimbabwean culture dictates that handling a sick person with gloves is dehumanising. Yet,
the transmission of HIV upon exposure to bodily fluids can be avoided by using protective latex gloves. In this instance, culture is problematic but it is rarely recognised as such because it is accepted as reality. That is where a rational motive (Schutz & Luckmann 1973: 6; Hughes & Sharrock 1980: 1) is applied to manage a problematic situation. In addition, African culture calls for families and society to care for people who are not well (Airhihenbuwa & Webster 2004: 5), but the existence of stigma against people with HIV leads to the non-observation of some cultural demands as people reflect on the threats that HIV poses to them.

Furthermore, African societies have their own cultural practices in treating sickness which can conflict with how HIV is managed. It is believed that HIV poses threats on traditional disease prevention, treatment and care in many African societies (Airhihenbuwa & Webster 2004: 5) because it requires people to manage it in a more Westernised than African way. For example, HIV cannot be deterred and cured by traditional means that involve, to a large extent, spiritual, religious and psychological intervention. Irrespective of this, many people consult traditional healers for the cure of HIV (Müller & Kanfer 2011: 459) because traditional healing is a fundamental reality in particular African societies. I therefore, explore how culture influences the research participants’ everyday experiences in my analysis of their lifeworld. I also explore how the women participants act rationally to align cultural demands with their medical conditions.

1.2.1.2 The lifeworld of an ageing body

Gerontologically, ageing is a natural process that everyone with a long life span encounters (Dannefer 2013: 793). Dannefer (2013: 797) goes on to identify ageing as “a process of cumulative disadvantages that is accompanied with life-changing consequences.” This
incorporates the decline of psychological and physical capabilities (Cohen 2006: 28) including lower energy, memory and cognitive abilities (James, Wilson, Barnes & Bennett 2011: 998). As a result, many people view ageing people as potential adult dependants because of the life impairments that make them dependant on other people for care and support (Keyes 2014: 8). Such aspects impact on the quality of life in older people. There are also issues of immunity changes to the ageing body, a natural process in which the immune system deteriorates as the body ages (Gomez, Boehmer & Kovacs 2005: 457). The changes result in older people facing greater susceptibility to diseases (Harman 1981: 7124). It is, therefore, important to look at the lifeworld of research participants in line with the influences of age on health and in particular how HIV affects the ageing body and impacts on lived experiences.

Furthermore, ageing often has a considerable bearing on the sexuality of women. Older women are stereotypically regarded as asexual and people who lack sexual interest. They are viewed as people who have “outgrown any semblance of sexual identity” (Dixon 2012: 1). In the social world, sex is associated with the physical attractiveness of the body (Emlet, Tangenberg & Siverson 2002: 237), which tends to disappear with age. The assumption that older people are asexual disregards the probability that older women can get infected with HIV. Older women may have limited sexual activities, but many of them may still be sexually active (Woloski-Wruble, Oliel, Leefsma & Hochner-Celnikier 2010: 2401). It is likely that some of the research participants got infected later in life through sexual contact, yet society considers them as people who are asexual. Issues of sexuality are, thus, dealt with in this study to establish their influence on the research participants’ experiences.

In addition, the social life of older people may be affected by the decline of physical ability and energy. Some scholars argue that the older one gets, the higher the chances are of giving
up on relationships and activities that are crucial to supporting one’s social life (Pinquart & Sorensen 2001: 247; Charles & Carstensen 2010: 384; Wallach & Brotman 2013: 1217). Others however, maintain that older people have improved personal relationships (Fingerman & Charles 2010: 172). Although other people regard it as a stereotype (Pinquart & Sorensen 2001: 245), older people often experience isolation (Berger & Berger 1975: 357; Van Manen 1990: 188; Wallach & Brotman 2013: 1215), loneliness, anxiety, widowhood and generalised unhappiness (Van Manen 1990: 188). Fingerman and Charles’ (2010: 174) position, however, is that some older people nurture interpersonal relationships positively. It is argued that older people spend the remaining time of their life avoiding conflicts and enhancing social problem solving strategies that strengthen their relationships (Blanchard-Fields 2007: 26; Fingerman & Charles 2010: 174). In addition, the reduction of social networks may afford them more time, commitment and closeness in their social relationships (Charles & Carstensen 2010: 388). Hence, some older people’s relationships get weakened while others get enhanced.

Since women generally have a longer life expectancy than men (Makiwane, Ndinda & Botsis 2012: 15), they often experience loss of company upon the death of a spouse and when a youngest child leaves home to live as an independent adult, resulting in what Van Manen calls “an empty nest syndrome” (Van Manen 1990: 187). Although many old people in African societies stay with other family members, some prefer to maintain less contact with their family members (Poindexter & Shippy 2008: 724). This often results in those who choose to live private lives receiving little social support. Some old people, especially those living with HIV, prefer to build new social networks among those with the same condition (Wallach & Brotman 2013: 1215). Such kind of networks are considered fragile because they normally do not last
as people die from HIV, AIDS\(^4\) and age-related illnesses (Pointexter & Shippy 2008: 724). An exploration of the research participants’ social life, therefore, enlightens us on how their experiences are impacted by age.

My exploration of the experiences of older people also focuses on the way their physical capabilities are impacted by age. The theory of disengagement in gerontology reflects on how age disconnects older people from active engagements. This theory, in its basic form, postulates that people withdraw voluntarily from active roles as they age and give way for younger ones (Cumming 1964: 3). Their physique deteriorates due to advanced age, and as is the case with research participants in this study, because of HIV too. As such, some disengage from rewarding responsibilities, which can create challenges in fulfilling their material needs (Van Manen 1990: 190; Wallach & Brotman 2013: 1215). For this reason, some scholars claim that the older some people get, the poorer they become (Barrientos, Gorman & Heslop 2003: 558).

Van Manen contends that the association of poverty and old age is strong, especially in older women since they lose some of the family income upon the death of their spouse (Van Manen 1990: 187). This can be worsened in situations where the spouse was the sole bread-winner in the family as is the case in many Zimbabwean families. In addition, their aging bodies cannot allow them to engage in income generating activities that can sustain them and their dependants particularly in cases where they also care for orphaned grandchildren. Thus, ageing brings along challenges to the everyday life in the lifeworld of the research participants as their engagements become limited.

\(^4\) AIDS stands for Acquired Immune Deficiency Syndrome
1.2.1.3 Typifications in the lifeworld

Inglis and Thorpe (2012: 96) define typifications as recipes for doing certain things in certain ways. Typifications occur within the lifeworld as primary common-sense ways of doing things (Kim & Berard 2009: 265) or the practical know-how for dealing with things in the world (Overgaard & Zahavi 2009: 102). They are embedded in the human knowledge of how things are in the outer world and through individual experiences (Kim & Berard 2009: 266). This means that typifications in everyday experiences are subjective to typifications in the wider society (Kim & Berard 2009: 265) where natural knowledge is socially shared and accepted.

Once typifications are institutionalised or deeply entrenched in social patterns, they form the basis for human actions and thoughts and are present in every person’s practical consciousness (Inglis & Thorpe 2012: 91&95). They also shape social institutions such as the family and gender relations (Inglis & Thorpe 2012: 95). Furthermore, typifications are continual and frequent if desired outcomes are accomplished (Schutz 1970: 116). Thus, people assume that systems remain valid in the future and that the past and present accomplishments are also possible in the future (Schutz 1970: 116). As a result, typifications are experienced as natural with a person not necessarily expected to think of new ways of doing things. Instead, typifications become generic and homogenous that they often dictate the whole process that will lead to a specific outcome.

It has to be acknowledged that typifications vary. There are “typical means” for “typical results”, “typical precepts” for “typical behaviour”, “typical motives” in “typical situations”, “typical actions” and “typical reactions”, “typical sequences” and “typical relations” (Kim & Berard 2009: 267). People reflect on the demands of the lifeworld or they critique their
immediate experiences in order to resolve problematic situations — ideally, logically and factually — depending on their motives or reasons (Husserl 1964: 14). Accordingly, there are typical actions in typical situations with typical consequences that are inspired by typical motives in the life of a woman who is growing old with HIV that need to be explored.

Alfred Schutz mentions in his analysis of typified actions and motives that there are the “in-order-to” motives and the “because” motives which depend on people’s practical interests (Overgaard & Zahavi 2009: 104; Flick, Kardorff & Steinke 2004: 68). On one hand, a person who typifies an action with the “in-order-to” motive aims to achieve something through that action (Overgaard & Zahavi 2009: 104). On the other hand, the person who typifies an action with a “because” motive aims to address problematic past experiences and circumstances that warrant a particular course of action (Overgaard & Zahavi 2009: 104). Alfred Schutz, therefore, suggests that social phenomena be understood by examining the explanations given by people to determine the goals and reasons for any action (Flick et al. 2004: 68). This shows that there is some degree of rationality in the common-sense world that people share. This view of the rational assumes that people base their actions on a strategy or they execute a well-thought-of course of action where its consequences are also analysed in advance to ascertain the appropriateness of such actions (Ruggerone 2013: 187).

A woman who disregards other treatment forms to take HIV medication (Antiretroviral Therapy) would be employing the treatment process within the “in-order-to” motive of living a healthier and longer life. She visits a medical facility assuming that she will consult a medical practitioner who is knowledgeable on the type of medicine that will work for her. She then takes the medicine, as prescribed, with the assumption that it is the right medicine that will make her better. When that medicine is finished, she repeats the same process and hopes to
get the same desired outcome because she believes that the previous successful actions she took will definitely work well in the future. Alfred Schutz and Thomas Luckmann (1973: 7) mention that successful previous actions can be repeated for as long as they are valid, the situation and conditions remain the same, and when one is still capable of doing it. Nonetheless, typified actions directed by the existing lifeworld’s common knowledge suggest that a person who is living with HIV can consider using traditional medicine to manage her health. Thus, a troublesome ARV side-effect like diarrhoea can be managed using a home-made concoction because that person knows how to do it through the traditional knowledge that exists in that society.

Typifications can also be formed on the basis of stereotypes, known as stereotypical typifications (Inglis & Thorpe 2012: 92). Stereotypes, as defined by Lindsey (1997: 2) are “oversimplified conceptions that people who belong to the same group or category share certain traits in common.” People with HIV are thus labelled flatly as those who behave and live the same and therefore deserve the same treatment. These stereotypical typifications are often experienced as natural ways of doing things because they are common among people who possess the same condition like HIV and AIDS. What is significant, however, is that once stereotypes are activated, they influence the levels of understanding of the targeted people (Bodenhausen & Macrae 2013: 16). Hence, they influence consciousness, opinions and actions (Bodenhausen & Macrae 2013: 2) either positively or negatively, depending on the motive of actions taken (Lindsey 1997: 2). But in most cases, stereotypes result in the stigmatisation and discrimination of people who are living with HIV. This study also considers stereotypical typifications in its attempt to uncover the experiences of women who are ageing with HIV and the effects, if any, of HIV-related stereotyping.
1.2.2 Lived experiences of women who are growing old with HIV

Jacobsen (2009: 10) used Jørgensen’s (1894: 17) definition of lived experiences as the everyday life as we live, sustain, renew, recreate and transform it. This indicates that lived experiences involve life as lived on a daily basis (Jacobsen 2009: 10), or life as we immediately experience it (Van Manen 1990: 9), or life as we experience something, such as a feeling or a type of person (Rogers 1983: 40). To a large extent, elements from a person’s life stories are incorporated in analysing lived experiences (Rogers 1983: 3). For this reason, phenomenologists are interested in exploring the nature of everyday life by asking questions such as: where is it lived? why it is lived? with whom it is lived? and when it is lived? (Jacobsen 2009: 10). Therefore, an understanding of the research participants’ lived experiences is mainly drawn from their narrated life-stories.

Rogers (1983: 37) points out that lived experiences are temporal, with things often occurring simultaneously and mostly shaped by past intentions. Thus, lived experiences are well thought of, interpretive and uniquely formed from past experiences and meanings that people attach to things around them (Rogers 1983: 38). Rogers argues further that the interpretive nature of experiences (past experiences) informs the future and helps people to assign meaning to the unfamiliar or unknown situations (Rogers 1983: 38-39). Thus, lived experiences are organised and can be epitomised through things already experienced.

Featherstone’s (1992: 161) concepts that guide sociologists in investigating lived experiences are stated as follows:

- An emphasis on the everyday routine, repetitive and taken for granted experiences, beliefs and practices,

- An emphasis on the pre-institutional zone of basic activities – their
reproduction and maintenance,

- An emphasis on situations that provide non-reflexive sense of engagement into existing experiences,

- An emphasis on the shared embodied sense of being together in activities outside or inside official institutional domains, and

- An emphasis on the diverse knowledge over rationality.

In the context of this study, and with reference to Featherstone’s (1992: 161) view, the research participants’ lived experiences are better understood if analysed in line with how they perform their everyday activities in accordance with their beliefs and practices as well as the shared perceptions that exist in their lifeworld. Their lived experiences must also be explored along the existing presuppositions of what counts as knowledge in their lifeworld so that people understand whether actions are directed by the common assumptions or by ordinary reasonableness.

1.2.3 Intersubjectivity

Intersubjectivity is a phenomenological concept that recognises that a person is in the world with others and that everyday life is influenced by our experience with or of other people and other things in the world (Sokolowski 2000: 152). It primarily deals with the ability of a person to connect with others (Teunissen 2014: 349) since no one person can create a human environment in isolation (Berger & Luckmann 1966: 51). Intersubjectivity also incorporates how people’s consciousness influences action and interactions in instances where different minds meet and perceive each other’s meaning with reference to an object (Percy 1958: 631). Intersubjectivity therefore, involves shared meanings, a collective understanding of a
phenomenon among people in the lifeworld and how people experience others’ minds (Sokolowski 2000: 152).

The commonness of the lifeworld makes it an intersubjective world where viewpoints, knowledge and beliefs are shared (Gurwitsch 1962: 52-53). Accordingly, the Schutzian view on intersubjectivity postulates that our actions are guided by our internal (cognitive) order that is mainly influenced by the commonly shared assumptions in the lifeworld where perspectives are reciprocal, standpoints are interchangeable and systems of relevance correspond (Ruggerone 2013: 187). At the core of the matter is the way a person connects with others and how shared assumptions impact on that person’s thoughts, judgements and actions. In this study, the concept of intersubjectivity is used to explore how research participants relate with other people who are growing old with HIV and how their experiences are influenced by what they see and know about their condition from the wider society. Therefore, a collective understanding of ageing with HIV is key to this study.

1.2.4 Consciousness

In line with Edmund Husserl’s view, being conscious means that one is in contact with things and is aware of them (Rogers 1983: 22). Consciousness involves people’s monitoring of their state of mind, for instance in monitoring their thoughts or senses as these are directed towards objects with what some scholars call intentionality (Rogers 1983: 22). This implies that every act of consciousness is associated with an object (Sokolowski 2000: 8). People’s engagements therefore, are directed by a realisation of things that surround them.
Phenomenologists are of the view that things that exist can only be reached or accessed through consciousness (Rogers 1983: 22). This suggests that if a person has a belief, fear, hope, desire or a conviction, it must be directed at something (Searle 1983: 1). The same applies to intention in that if one has an intention, it ought to be an intention towards something (Searle 1983: 1). This puts a link between the mind, actions and the things that surround people.

According to Billington, Hockey and Strawbridge (1998: 244) social life can be purposeful and reflexive — it can be made possible by reflecting, becoming aware of and creating meaning to the things that surround us. As such, meaningful lived experiences are established in deep consciousness (Ritzter 1983: 202). Consciousness also involves experiences that are created by actions, and through memory, perceptions, expectations and interpretations (Zhou 2010: 311). A person therefore becomes conscious of something through past experiences, awareness, expectations and understanding of a phenomenon. Alfred Schutz mentions that, before a person carries out an act of consciousness, he or she would have a picture in mind of what he or she is going to do (Schutz & Luckmann 1973: 15). Similarly, Edmund Husserl, Alfred Schutz’s predecessor, talks about critique of cognition and how a person is able to reflect philosophically on an object (Husserl 1964: 14). This means that acts of consciousness are projected and are not random. In a phenomenological perspective, it means that a person is aware of the things in the lifeworld and that perceptions, understandings and intentionality influence everyday experiences. What we consider as reality or unreal to us is made so because of our conscious actions (Rogers 1983: 22). In this case, consciousness and reality are not independent of each other.

In this study, I explore research participants’ consciousness in relation to living with HIV into old age. On one hand, HIV is known for its ability to challenge the normal functioning of the
body. On the other hand, ageing is a natural biological process that effect changes to the mental and physical appearance of a person (Billington et al. 1998: 111). Living with such challenges to the body induces acts of consciousness that are crucial to how the research participants experience their everyday life. Their experiences can be understood also by looking at the different realities that they create through their conscious acts.

It is important to examine if there are some acts of consciousness in this study that the research participants typify since acts of consciousness are postulated to be continuous (Rogers 1983: 26). The acts of consciousness are informed by either expectations from past intentional acts (retentions) or expectations from pending intentional acts (protentions) (Rogers 1983: 26). In this case, conscious actions are directed by memory and expectations in creating lived experiences.

1.3 The social construction of reality

The social construction of reality theoretical approach developed from the ideas by scholars including Alfred Schutz, Peter Berger and Thomas Luckmann (Ritzer 1983: 208; Inglis & Thorpe 2012: 93) is applied in this study to explore the research participants’ subjective meanings as their experiences are influenced by social forces, social order and social structures. Generally, reality is culturally and historically negotiated (Ritzer 1983: 203; Creswell 2007: 21; Creswell 2013: 24) with experiences being influenced by society’s beliefs, practices, norms, morals, laws, knowledge, attitudes and other habits adopted by individuals as members of a society (Rambo & Chan 1990: 636; Gausset 2001: 510). These cultural and historical meanings, especially those linked to sexuality, often regulate sexual experiences and behaviours (Setel 1999: 11; Parker 2001: 166). Meanings, therefore, exist in the culture of a
society and are shared and accessible to others (Ritzer 1983: 203; Lopez & Willis 2004: 728). Reality is also (re)constructed by individuals as they interact with each other and as they forge meanings of a situation (Creswell 2007: 21). Despite individual agency in challenging and (re)constructing normative reality, Berger and Luckmann (1966: 19) and Searle (1995: 2) propose that social structure dominates. The result is that people mostly align their thoughts, attitudes and actions with dominant social norms, and with what others make of the phenomenon being experienced.

When a person is confronted by a crisis or limitation that disturbs social order and creates anxiety and uncertainties (Holzner 1972: 13) he or she might adopt acquired meanings in what Harris (2008: 232) terms interpretive constructions of social reality. This means that meanings that people take for granted when co-creating a stable socially shared world can be disturbed by a problematic situation such as HIV and ageing. Holzner (1972: 13) calls this situation where normality is confronted with threats, a reality shock. A person facing such a reality shock has to reconstruct reality in order to live a self-fulfilling or meaningful life. In the case of an older woman infected with HIV, she has to deal with limitations and uncertainties that HIV brings to an ageing body in a way that preserves or recreates social order. Hence, the experiences of research participants are explored with regard to how they (re)construct their individual and social reality as they live with HIV into old age.

I explore further how research participants create meanings in the face of the challenges they experience, especially how certain structures or arrangements impact on their experiences. Meanings and structures are two interconnected concepts that impact on one’s lifeworld (Baars & Phillipson 2014: 4). Older people can face, for instance, physical structural challenges in navigating their everyday life and these challenges can compel them to generate new ways of
living a meaningful life. Some find alternative ways of getting along rather than allow problematic structures to be a hindrance or wait for the structures to be changed (Baars & Phillipson 2014: 3). The important issue here is how ageing people with HIV organise the physical and social into meaningful engagements.

People not infected with HIV draw on their own subjective understanding when dealing with those living with HIV and sometimes fail to see past someone’s HIV-positive status. In some instances, society identifies differences between non-HIV-infected people and those who are infected with HIV, resulting in discriminatory acts and thoughts towards those who are HIV-positive (Cameron 2014: 43). Consequently, those living with HIV can self-exclude or socially-isolate themselves owing to the influence of other people’s views on their social relations. They internalise the shame, humiliation and social rejection that they see in the society often according to people who are living with HIV (Fife & Wright 2000: 50). In addition, HIV-positive people who view their condition negatively often develop an imaginative projection and feel as if other people have the same negativity towards HIV as they themselves do. The likely effect is that many of those who are HIV-positive end up forming social networks with people who share the same views, experiences and understanding of living with HIV because they relate to each other. Thus, the ‘unfriendly’ social world plays a role in the way the HIV-positive people choose who to socialise with.

Since meanings attached to HIV and AIDS can be informed by cultural contexts as discussed in section 1.2.1.1 (pg.11), research participants’ experiences in relation to living with HIV can be culturally defined. There are arguments that culture limits talk on women’s sexuality (Emlet, Tangenberg & Siverson 2002: 237) and there is a high level of passiveness, in the social milieu, of discussions on HIV in Zimbabwe (Mawadza 2004: 420; Rödlach 2006: 21; Nhamo,
Campbell & Gregson 2010: 1662). Sexuality in this context refers to both sexual identity and sexual networks as well as practices (Blackwood 2000: 223). It becomes difficult for older women to talk about their sexual networks and practices with family members and friends because culture might consider it a taboo. HIV is also associated with sex and body parts that are private and regarded in Zimbabwean vernacular languages and cultures as not fit for communal discussion (Mawadza 2004: 420). In addition, older people may feel uncomfortable to discuss their sexual issues with doctors, or doctors may feel uncomfortable discussing sexual issues with their older patients (Emlet, Gusz, & Dumont 2003: 45; Lindau, Leitsch, Lundberg & Jerome 2006: 750). People’s engagements are therefore guided by what is acceptable in their society.

1.3.1 The social construction of age and HIV

As mentioned earlier, the life experiences of women who are growing old with HIV can also be understood from an exploration of the way in which their condition is socially constructed in their society. Aspects of reality in everyday life are therefore influenced by the world in which people live and the situation they find themselves in (Lopez & Willis 2004: 728). How people understand and experience the nature of HIV and ageing varies among people in what Taylor (2001: 793) calls micro and macro perspectives, where levels of analysis of a situation vary from interpersonal to larger social processes.

Aging is a micro-level biological process that can be subjected to macro-level social definitions (Berger & Berger 1975: 357). In most cases, what clinicians view as a biological process can mean something different to individuals experiencing this process within a society (Billington, Hockey & Strawbridge 1998: 111). This implies that to be old or to be called aged depends on
societal classifications. Society might classify a woman in her fifties under the ‘aged people’, whereas clinicians consider it as middle-age. My research participants call each other Grandmothers regardless of age (see chapter 4) because their society accords a person with a grandchild status, and it can be interpreted as disrespect not to call that person with the title Grandmother.

Furthermore, society might view HIV in terms of threats to health. People can assume that someone is HIV-positive basing on the outer physical appearance of that person, whereas clinically, the presence of HIV can only be detected through an HIV test. Even HIV-related symptoms like confusion and mental disorders can be interpreted by society as the effects of witchcraft, while medical doctors would diagnose it as the side effects of HIV treatment. And interestingly, what is considered as a mental illness in an African society can be viewed as a normal state of mind in an American society (Berger & Berger 1975: 357). Therefore, various issues determine the way people give meaning (neosis) to a situation and the meaning that people establish within a given situation (neoma) (Rogers 1983: 23).

1.3.2 Creating meaning

My exploration of how research participants create reality in the face of the situations they find themselves in, focuses on how they understand and organise aspects of life, in what can be referred to as meaning-making. Social reality is created through assigning sense to, or making sense of the world around us (Cicourel 1971: 136). Making sense of the everyday life implies that people use particular lenses to view a social phenomenon or a situation in which they are. Holzner (1972: 11) calls these lenses the frames of reference, which generally provide the basis of people’s judgements and perceptions. This makes sense-making or meaning establishment
an ongoing and socially constructed everyday process (Anderson 1991: 29) where people assign meanings to actual everyday experiences due to the fact that they are located in that context (Holzner 1972: 6) and oriented consciously in a particular way towards that experience. The interpretive approach which underpins this research goes beyond just describing perceptions as it also unpacks meanings that entrench life experiences (Lopez & Willis 2004: 728).

As discussed earlier, meaning is also created through sharing the same lifeworld (Schutz & Luckmann 1973: 32). For this reason, meanings are usually “contextually constructed as intersubjective” (Anderson 1991: 35) and people “see reality as a unitary connected world in which we live as unitary, integral selves” (Holzner 1972: 1). Thus, meanings involve relations between people (Anderson 1991: 29) and are created out of engagements with others and the nature of reality they face (Galvan & Parker 2011: 58). Therefore, life in a shared world entails shared meanings and realities as people include each other in their awareness (Holzner 1972: 6). However, peoples’ experiences with others and the things around them lead to the creation of new meanings based on valuing things that make sense in and of their experiences (Jacobsen 2009: 10). As Alfred Schutz postulates, meanings are those social aspects of the social world that people consider important (Ritzer 1983: 202-203). This implies that no experience is without meaning (Rogers 1983: 37) and sense-making can depend on the shared and valid reality that exists in a society.

The process of constructing and establishing meaning is, to a large extent, subject to consciousness, especially, where a person tries to relate and adapt to changes in his or her life. The notion of new meanings and consciousness can be explained in the model by Hendricks (1999:193) below:
Fig. 1: Consciousness and meaning-making model (Hendricks 1999:193)

Hendricks’ model shows that every day and past experiences form the lifeworld where meanings are constructed in line with those experiences. A person who is conscious of such experiences defines or re-defines meaning accordingly by focusing on things that are contextually relevant to him or her. Thus, action is something that is defined by meaning (Schutz 1972: xix) and involves aspects of consciousness (Ritzer 1983: 202) or a realisation of challenges associated with the lifeworld. A person’s experiences and practical consciousness are therefore co-constituting in the meaning-making process where, for example, major crises associated with ageing, like chronic illness, have to be faced.

In summary, human agency shape social structures and conversely, social structures shape human agency in a cyclic process of construction and re-construction of reality. Therefore, the social world shapes experiences, and meanings are created by people’s social encounters.
1.4 Existential phenomenology

I use aspects of existential phenomenology, in addition to phenomenology and the social construction of reality, as part of my theoretical paradigm for this research. Existential phenomenology basically deals with experiences of people in the world where feelings and emotions as well as an individual’s central role in the formation of everyday social life are studied (Craib 1976: 2; Douglas 1977: vii; Kotarba 2009: 140). Jean Paul Sartre who founded the notion of existential thinking, centred his ideas on movement and change, with the recognition that change is a regular feature of people’s lives (Kotarba 2009: 140). In line with this philosophy, existential phenomenology views perceptions and consciousness within individuals as located in particular times, places and lifeworlds (Inglis & Thorpe 2012: 101).

David Hume, a radical Scottish philosopher, asserts that emotions are founded in the sensations that are brought about by perceptions of the mind (Meisenhelder 1982: 197). People’s emotions are thus evoked by their perceptions of a certain phenomenon that is experienced at a particular time, place and lifeworld. These sensations and emotional responses to a phenomenon make existentialism not only philosophical, but also a “sensibility, a way of life, a passion for living, an orientation to the changes in lived experiences” (Kotarba 2009: 141). This section, therefore, discusses the psychological aspects that are associated with changes in life as a result of age and HIV.

Kotarba (2009: 140) mentions that the “how do you feel?” question is best answered by existential phenomenology because the phenomenology of feelings is about a person’s body, mind, spirit and feelings that are attached to these (Scheler 1967: 23). Karl Jaspers, a German psychiatrist and philosopher maintains that what is most important is the ability of a person to
assess the significance of feelings with regard to life (Leben) and its purpose (Lebenszwecke) (Rosfort & Stanghellini 2014: 154). For example, positive feelings such as joy promote a purpose in life and negative feelings that include distaste stand as hindrances (Rosfort & Stanghellini 2014: 154). The existence of research participants in the shared everyday world and their emotions are therefore significant in the context of this research as it explores their feelings towards an HIV infection and its implication on their age.

Furthermore, human feelings are varied. There are bodily feelings and those that are psychological or directed at the mind and spirit (Scheler 1967: 26; Rosfort & Stanghellini 2014: 154). One can feel uncomfortable in sickness (bodily feelings), or stressed by sickness (mental feelings) (Scheler 1967: 26), or one can feel at peace and adequate even if he or she has a condition like HIV (spiritual feelings). Bodily feelings, which are present because of research participants’ medical condition, can be classified into sensory and vital feelings. Sensory feelings are experienced in a particular or present moment in a person’s body and are related to physical symptoms (Rosfort & Stanghellini 2014: 155). They lack continued meaning (Scheler 1967: 23-24). Hence, they cannot be experienced by memory or expectation of feeling (Scheler 1967: 23) because they emanate from fleshly pain experienced at that particular time. Vital feelings are, however, not localised to a certain part of the body (Rosfort & Stanghellini 2014: 154) and have meanings that can be reproduced (Scheler 1967: 23-24) because they involve the whole body.

Furthermore, mental feelings like sadness and joy (Rosfort & Stanghellini 2014: 154) relate to the ‘I’ (the person) (Scheler 1967: 22) and express how a person feels about a certain experience or situation. For example, mental feelings deal with how research participants feel about the reality of living with a despised condition in their society. Lastly, spiritual feelings are
subjectively connected to hope, new meanings and purpose in life that occur when adapting to a condition, in this case an HIV diagnosis. Spiritual feelings also involve experiences when a person is fostering lifestyle changes (Lutz, Kremer & Ironson 2011: 398) like adopting a healthy diet or reducing the number of sexual partners.

A further contextualisation of the concept of feelings shows that HIV is perceived as a threat to a person’s self and existence (Anderson & Spencer 2013: 330) because of its ability to pose physical and psychological threats to the body. As a result, some people can experience feelings of agony and pain due to HIV infection, while others develop positive changes such as inner strength and lifestyle changes (Tedeschi & Calhoun 2004: 1). Applying the existential phenomenology theory assists in the description and interpretation of the feelings and emotions of research participants as they face life changing experiences, such as ageing with bodily afflictions, mental distress and spiritual feelings, while growing old with HIV.

1.5 A gender framework in relation to older women with HIV

Gender is important in social life and it is often taken for granted because people usually accept gendered interactions as a normal or part of reality owing to the fact that they are passed on from generation to generation. Sociologically, gender focuses mainly on examining how differences between men and women are enabled or constrained by the social environment (Holmes 2007: 18). Usually, people are brought up to believe that the sex of a person determines his or her actions and interactions. Emphasis is put on acting in line with masculine and feminine distinctions — the manliness and womanliness of people as expected by society. In line with Lindsey’s (1997: 2) position, research participants, as women in a society, expect, and are expected to show a certain conduct and behaviour which is ordered by the socially
constructed norms, privileges and responsibilities that accompany their social status. Hence, their experiences as women who are growing old with HIV are worth exploring in this study.

The social conflict theory postulates that social structure is power based, with the superior dominating others (Lindsey 1997: 7). The social theory initially followed Karl Max’s assertions on class struggle whereby the powerful people control the means of production and was later refined to involve social relations including relationships between men and women, husbands and wives and many interpersonal connections (Lindsey 1997: 7). The social conflict theory, in relation to gender, applies when men possess authority over women which result in gender inequalities (Lindsey 1997: 7). More generally, gender distinguishes the experiences of men and women (Emlet, Tangenberg & Siverson 2002: 235), who are widely accepted as differently positioned in society. Gender fits well within the discourses of social conflict since it is associated with issues of power as postulated by Lindsey (1997: 7) and Hillman (2007: 62). Therefore, I analyse the experiences of research participants in relation to how the social environment impacts on their experiences as women.

Early founders of sociology presupposed that the innate nature of women makes them different from men in their logical, emotional and moral aptitudes (Chafetz 2006: 4). The social subordination of women was pursued by sociologists including Emile Durkheim and Georg Simmel who gave biological explanations to the subordination of women (Chafetz 2006: 5). Their philosophical assertions elevated men’s dominance over women and as Witz (2001: 353) notes, women were unfortunately relegated to the wastelands of Georg Simmel’s philosophical imaginations while men entered into the “more fertile and productive workings of his sociological imagination.” The resultant scenario is one where women are confined to becoming men’s subordinates in patriarchal societies.
Since people are socialised along gender distinctions and internalise, from an early age, the idea that women and men have different bodies, needs and capabilities (Chafetz 2006: 4; Holmes 2007:1), it often results in sexism whereby people perceive one gender’s social status as superior to the other (Lindsey 1997: 2). Society has rules about what is desirable and proper in interpersonal relationships as well as in social institutions (Auerbach, Parkhurst & Caceres 2011: S294). As such, gender influences the behaviours, persona and identities of people (Wharton 2005: 54) in accordance with what is socially acceptable. Therefore, an application of gender theories in this study assist in the identification of specific issues related to women’s experiences of living with HIV, especially how their social status impacts on their conduct.

In the context of this study, I begin with the assumption that the experiences of a woman who is growing old with HIV can be gendered. A woman can find herself in a situation where her life is threatened by a medical condition such as HIV with little or no power to protect herself. She might not effect reasonable courses of action to impede the sexual transmission of HIV because the norms dominant in her society dictate that she employs a passive stance in a heterosexual relationship. Lindsey (1997: 2) points out that freedom of action can be heavily compromised when roles, behaviours, expectations, responsibilities and privileges are rigidly defined in a society. Thus, research participants might have limited platforms to express themselves and act freely in as far as HIV prevention, treatment and care are concerned.

In conclusion, the interpretive approach is employed in this study to get first-hand accounts of research participants’ experiences. The theoretical framework guiding this study includes phenomenology, the social construction of reality, existential phenomenology and gender. An examination of the lifeworld, lived experiences, intersubjective experiences and consciousness lead to an understanding of research participants’ phenomenological experiences. The social
construction of reality theory exposes how research participants’ experiences can be influenced by social forces existing in the society and also how they create reality by their attitudes, habits and behaviours as they forge meanings around growing old with HIV. Furthermore, research participants’ reactions, emotions and feelings towards their condition(s) are explored using some aspects of existential phenomenology. Lastly, gender theories are applied in this study in an attempt to understand how the femaleness of research participants impacts on their experiences.
CHAPTER 2 — LITERATURE REVIEW

A review of available research on my study of the experiences of Zimbabwean women within the context of HIV and ageing draws on what Flick (2009: 49) identifies as current ideas on what is known or unknown about the phenomenon under study. HIV and ageing is a growing field of study as more and more people are surviving longer with HIV (High 2012: 1; Nyirenda, Chatterji, Falkingham, Mutevedzi, Hosegood, Evandrou, Kowal & Newell 2012: 259). Demographic predictions indicate that approximately 1.6 billion people will be older than sixty years by 2050 in developing countries (UN 2013: xvii), including those infected with HIV. However, research on ageing and HIV, especially social science research, is very limited (Sankar, Nevedal, Neufeld, Berry, Luborsky, 2011: 1187; Rosenfeld, Ridge & Lob 2014: 21; UNAIDS 2016: 1). More attention is given to the medical connection between HIV and ageing (Zhao & Goetz 2011: 1210; Hearps, Maisa, Cheng, Angelovich, Lichtfuss, Palmer, Landay, Jaworowski & Crowe, 2012: 843; Pathai, Lawn, Gilbert, McGuinness, McGlynn, Weiss, Port, Christ, Barclay, Wood & Bekker 2013: 2375).

Most HIV programmes, globally and locally, focus on people up to the age of forty-nine (Negin & Cumming 2010: 847) leaving out older people. More importantly, many studies focus on older people as carers of AIDS orphans, and not on older people as the infected population (Negin & Cumming 2010: 847; Oduaran & Oduaran 2010: 95; Casale 2011: 1265; Skovdal, Campbell, Madanhire, Nyamukapa & Gregson 2011: 957). This chapter therefore, reviews literature on the phenomenon of ageing with HIV in an effort to outline the background to the research problem.
2.1 The Human Immunodeficiency Virus (HIV) prevalence

An overview of HIV prevalence is important in understanding the magnitude of the epidemic. HIV is widely recognised as a global health problem (Hemelaar 2012: 182; Ortblad, Lozano & Murray 2013: 2003) with sub-Saharan Africa holding the highest number of people as noted in the way region accounts for 66% of global HIV new infections i.e. HIV incidence (UNAIDS 2015: 2). Zimbabwe has approximately 1.4 million people living with HIV and AIDS (UNAIDS 2014: 2) with women showing a higher prevalence (51.4%) than men (UNAIDS 2014: 2). The 2015 World Health Organisation (WHO) HIV estimates show that the majority of people living with HIV and AIDS globally are women (UNAIDS 2015). Gender disparities between men and women that are discussed later in this chapter explain some of the reasons and implications of these statistics. Surveys establishing the prevalence of HIV and AIDS among older populations in sub-Saharan Africa include one by Negin and Cumming (2010: 248) that found out that approximately three million people older than fifty years were living with HIV and AIDS in 2007. Zimbabwe is one of the countries whose demographic and health surveys are reviewed in the Negin and Cumming’s 2010 study and showed the highest number of people older than fifty years living with HIV and AIDS (Negin & Cumming 2010: 848). The overall picture of the HIV epidemic therefore reveals that HIV is infecting and affecting many people regardless of age.

2.2 HIV and ageing in women

An increase in the number of women infected by HIV witnessed in the 1990s led to a huge focus on women and HIV. The 1990s discourses about HIV and ageing started to emerge along with the establishment of networks to support infected women (Wilton 1994: 1). The increase
of women infected with HIV started to eclipse the interpretation of HIV and AIDS as a condition for homosexual males (Doyal 1994: 12; Farmer 1996: 27). Hence, HIV in women came under the spotlight, although the studies were mostly concentrated on Western countries as reflected in the studies by Clark and Bessinger (1997: 341), Brown and Sankar (1998: 865) and Zablotsky (1998: 760).

Generally, women living with HIV often face both medical and social problems that are associated with the HIV epidemic (Mbonu, van den Borne & De Vries 2009: 1). In addition to the biomedical challenges, they live within challenging social institutions, networks and structures that impact greatly on their lived experiences. Auerbach, Parkhurst and Caceres (2011: S294) attribute this to social factors such as values, norms, networks, structures and traditions that influence human thoughts and action. The social structures, including acceptable principles on which social relations are made, act as rules that guide social interactions (Van Willigen 2015:4). Thus, African women’s experiences of living with HIV are arguably viewed as difficult because of these social norms as noted in the case of sexual norms, which tend to be more lenient on men (Duffy 2005: 23). Such social environments often create vulnerabilities to acquired conditions like HIV because they disempower women from engaging boldly with issues of concern. Other scholars found that older people living with HIV can overcome such difficulties owing to the wisdom that comes with age, by discerning the things that matter most to them (Siegel, Raveis & Karus 1998: 686) and exercising discretion in choosing social relations and networks (Van Willigen 2015:4). As a result, it is possible that older people create networks that involve other people sharing similar conditions.
2.3 HIV and the lifeworld of a woman who is growing old with HIV

As pointed out in the theory chapter (section 1.2, pg.10), the lifeworld which is the ordinary everyday world in which people operate (Inglis & Thorpe 2012: 90), can have unwelcome and often unpleasant realisations with regard to problematic situations (Ritzer & Goodman 2004; Inglis & Thorpe 2012: 90). In this case, the effects of HIV to the ageing body are one of the contextual and problematic factors underlying the research participants’ lifeworlds that lead to the unpleasant realisations. I present, in this section, the most common HIV-related conditions that affect women as they age with HIV, noting that most of the degradation caused by biomedical conditions evokes social ridicule with a possibility of making research participants misfits in their society.

The main characteristic of HIV is its ability to destroy the immune system (CDC 2013). HIV infects the body by attacking the CD4+ T cells that are responsible for protecting the body against infections (Hazenberg, Hamann, Schuitemaker & Miedema 2000: 285; Picker & Watkins 2005: 430; CDC 2013). HIV collapses the immune system and leaves the body prone to opportunistic infections if it is left untreated for a long time, which signal the manifestation of long-term HIV infection: Acquired Immune Deficiency Syndrome (AIDS) (Hazenberg et al. 2000: 285; Picker & Watkins 2005: 430; CDC 2013). A person, at this stage, can be incapacitated to the extent of being bed-ridden, a situation some Zimbabweans stereotypically refer to as the ‘Jehovah ndouyako’ (Mawadza 2004: 429) – literally translating to the ‘Lord I am coming home’ situation in which death is imminent. Thus, the ordinary everyday world of the research participants can be influenced by the effects of HIV on the body, which in turn may impact negatively on the social components of their life because of how society views people in that state and how the infected respond to society’s perceptions.
2.4 Social construction of reality and stigma

Stigma refers to discrediting attributes that people attach to others, the effects of which undermine and discredit a person (Goffman 2009: 3). Thus stigmatised people possess a minor social status that is generally categorised as neither normal nor good (Katz 2014: 1). Goffman describes how stigma reveals its effects on social identity through societal creation of differences between ‘them’ and ‘us’ (Goffman 2009: 3) where those who are considered different or deviant are treated with a negative and prejudicial attitude. Social distinctness is common in society as evidenced by the case of those infected with HIV calling themselves ‘The AIDS people’ as reflected in Campbell, Skovdal, Madanhire, Mugurungi, Gregson, and Nyamukapa’s (2011:1004) study on HIV treatment and stigma in Zimbabwe. This sub-section, therefore, discusses how people construct reality in the face of negative social forces from people who discredit those who are living with HIV.

The actual experience or existence of discrimination due to a person’s stigmatised condition is referred to as enacted stigma (Fay, Baral, Trapence, Motimedi, Umar, lipinge, Dausab, Wirtz & Beyrer 2011: 1089). It manifests through the construction of stigmatising actions such as “identification, labelling, ostracism, distancing, avoidance, isolation, or segregation” (Phillips 2011: 306-307). As per this study’s focus, factors that fuel HIV stigma that are common in Zimbabwe include fear of contagion and moral judgement (Campbell, Skovdal, Mupambireyi & Gregson 2010: 978). As a result, people create situations to avoid being in contact with the HIV infected. For example, some people stop visiting, shaking hands, eating, drinking or sharing items with people who are known or assumed to be living with HIV (Deribew, Abebe, Apers, Jira, Tesfaye, Shifa, Abdisa, Woldemichael, Deribie, Bezabih, Aseffa & Colebunders
Nonetheless, the affected people’s reaction to these stigmatising actions depends largely on how they perceive their condition.

Stigma can also be perceived from the way an individual considers how other people would react if they become aware of his or her stigmatised condition (Fay et al. 2011: 1089). Such a person gets concerned with the negative public attitudes and the fear of a negative self-image (Varni, Miller, McCuin & Solomon 2012: 130) related to an HIV infection. In such a process, people internalise stigma and allow negative behaviours and stereotypes in the external world to interfere with their internal experiences (Phillips 2011: 307). The emotional process often involves feelings of blame and shame in which one, for example, feels bad about his or her HIV status and perceives that he or she is in that situation because of the actions of others.

A person with HIV can also sense the fear of contagion that one has upon casual contact, or conversely, can notice that a person displays sympathy and pity for their condition (Phillips 2011: 306). This is what Katz (2014: 3) refers to as the visibility of perceptibility where certain actions are motivated by a known or a gossiped about stigmatised condition. People therefore react differently towards others upon learning that they possess a stigmatised condition. In addition, perceived stigma can emanate from people recognising that someone is blaming them for their condition or is assigning guilt and punishment because of their HIV-positive status (Phillips 2011: 306). This is often referred to as perceived responsibility. The condition is often viewed as acquired voluntarily through negligence and self-indulgence (Katz 2014: 4). Under such circumstances, a person usually suffers a great deal of low self-esteem (Katz 2014: 3) which in turn affects his or her social interactions.
Stigma can be heightened when physical symptoms of an HIV infection, which can be difficult to conceal, manifest in a person’s body (Gilbert & Walker 2010: 140; Stutterheim, Bos, Pryor, Brands, Liebregts & Schaalmam 2011: 382). An HIV infection and its treatment can have physical indicators that include the thinning of hair, skin irritations and abscessed and scarred lips (Nolen 2007: 65). Such threats to the physical appearance of a woman’s body can result in unfavourable interactions. People, especially men, can find her unappealing and thereby causing limited social connections. Other studies reveal that people with visible stigmatised symptoms of HIV seek less social support than those without (Berger, Ferrans & Lashley 2001: 528; Gilbert & Walker 2010: 140; Fay et al. 2011: 1089; Stutterheim et al. 2011: 388). Therefore, people living with HIV may limit social contact or try as much as possible to disguise HIV because of concerns about the social ramifications associated with HIV.

However, people do not always feel or react negatively towards those who possess a stigmatised condition. There are some who empathise with the excluded (Katz 2014: 3). Others indeed get concerned and feel distressed about someone’s agony or discomfort and offer respect to those trying to overcome a stigmatised condition (Katz 2014: 4). Such positive actions play a role in eliminating fears of perceived stigma in those who are living with HIV (Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter & Chassany 2012: 501). All in all, the presence or absence of stigma impacts on the experiences of those who are living with a stigmatised condition in that it affects their social engagements. In conclusion, people with HIV are likely to be stigmatised because they have a health condition that is associated with negative attributes like promiscuity, infectiousness, and incurability (Mawar, Sahay, Pandit & Muhajan 2005: 472). For this and many other reasons, stigma acts as a social construct as people conceive ways of interacting with those that are
infected with HIV (Taylor 2001: 792). Similarly, those targeted by stigma construct ways of coping and creating order in their lives as they experience or perceive these acts of stigma.

2.4.1 How HIV and age can be socially constructed

People analyse a situation and assign social definitions to that situation as referred to in previous discussions on the social construction of reality in the theory chapter (section 1.3.1, pg.27). This also applies to how HIV and ageing are viewed in societies. In many African societies, sickness, even HIV-related, is mainly associated with witchcraft (Bogart, Skinner, Weinhardt, Glasman, Sitzler, Toefy & Kalichman 2011: 181; Tenkorang, Gyimah, Maticka-Tyndale & Adjei 2011: 1001; Mbona 2012: 5). There is a general belief in these African societies that the effects of witchcraft can be overturned through spiritual and traditional means (Mbona 2012: 6). This belief misleads some HIV-positive people, especially those who believe that they would have been bewitched, into thinking that HIV can be cured through consulting traditional healers instead of getting the prescribed and proven Western HIV medication. In addition, associating HIV with witchcraft can make people disregard appropriate preventive measures because they would be viewing HIV as a natural occurrence (Bogart et al. 2011: 181; Tenkorang et al. 2011: 1001). The existence of such assumptions in the research participants’ ordinary everyday world might compel them to believe that the disruptions caused by HIV are perpetrated by witches, resulting in them not combating HIV accordingly.

Furthermore, HIV is widely regarded as a punishment for deviant behaviour in many African societies (Amuri, Mitchell, Crockcroft & Andersson 2011: 379; Svensson 2014: 569). Traditionally, sickness in Zimbabwe is regarded as punishment from the ancestors for certain culturally-unacceptable behaviour (Mawadza 2004: 420) as there is the general belief that there
is a connection between the earthly and the spiritual world with family ancestors controlling the living (Duffy 2005: 26). A majority of Zimbabwean Christians also regard HIV as a punishment from God for the sins of promiscuity and lewd sexual practices (Nyblade, Pande, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo & Bond 2003: 19; Mbona 2012: 8). In addition, the fact that HIV is stereotypically associated with socially undesirable behaviours like promiscuity and homosexuality, results in some people condemning those who have HIV as sinners and outcasts with a moral personality flaw who deliberately brought sickness to themselves (Amanze 2007: 28; Amuri, Mitchell, Crockcroft & Andersson 2011: 379). This leads to the blaming of the infected as highlighted through popular Shona stereotypes such as ‘aiwanza magemu’ which translates to ‘the person was a player and someone involved in many sexual activities’ (Mawadza 2004: 431).

Such moral judgements often lead to the stigmatisation of the HIV infected because they are often viewed as having contravened certain social norms. Therefore, a person who contracts HIV can be judged on deeds, or imagined deeds, that are socially constructed as misdeeds associated with immorality and a sinful sexual life. In addition, a person can become prone to what Mawar, Sahay, Pandit and Muhajan (2005: 472) term negative and prejudicial reactions, such as ridicule, rejection and isolation, from people who feel that they should bear the responsibility for their condition.

However, sometimes the HIV infected are viewed as mere victims of misfortune by people who empathise and assess their condition from a positive perspective (Muturi & An 2010: 396). People in Zimbabwe use the term ‘akahakwa’, translating literary to ‘they were roughly caught’, which means that the infected person did not deliberately bring HIV on him or herself (Mawadza 2004: 431). Women are mostly viewed as victims to HIV infection through their
husbands or male partners (de Souza 2010: 250; McDonald 2012: 14). They are seen as innocent victims who are ill-equipped to deal with HIV in patriarchal societies (Horne 2012: 139). Thus, there also exists in society an element of victimisation and blame of the male partner for infecting a seemingly ‘powerless’ female.

In addition, older women live in a society where other people think that they are too old to have HIV (Emlet 2006: 781). The assumption that most people hold is that, since HIV is mainly transmitted sexually in sub-Saharan Africa, older people cannot have HIV because they are asexual (Lindau, Leitsch, Lundberg & Jerome 2006: 747; Negin & Cumming 2010: 851). Uninformed attitudes regard sex as mostly associated with the physical attractiveness of the body and sexual appetite, both of which deteriorate with age (Emlet Tangenberg & Siverson 2002: 237). As a result, an older person who is known to be living with HIV is likely to face double stigma that is age and HIV-related (Lazarus & Nielsen 2010: 480). The reality in most cases is that many older people are still sexually active or contracted HIV while they were younger and are only growing old with it.

The belief that HIV is associated with young people can impact negatively on how older people respond to HIV (Hillman 2007: 54). Some studies report that older people tend to have a low perception of risk of HIV infection (Emlet, Tangenberg & Siverson 2002: 234; Theall, Elifson & Sterk 2003: 423; Orel, Stelle, Watson & Bunner 2010: 355; High 2012: 1). Yet they may be exposing themselves to practices such as unprotected sex that can result in HIV transmission. Incidentally, some people’s embracing of the conspiracy that HIV is a modern Western weapon against the African population (Mawadza 2004: 424; Rödlach 2006: 26; Mbona 2012: 6) hampers the widespread use of condoms which have a high efficacy in preventing the sexual transmission of HIV. Some people even suspect that condoms are
infected with HIV and avoid their use (Rödlach 2006: 14; Mbona 2012: 6). Nonetheless, health promotional messages, such as those relating to condom use, are argued as having a positive impact if they are culturally contextualised (Muturi & An 2010: 398) and age-appropriate for them to have meaning to the elderly.

There are other studies that show that the older one lives with HIV the better in terms of wisdom and resilience to negative social effects of HIV. Emlet, Tozay and Raveis (2010: 1) report on the constitution of resilience in ageing with HIV and better management of the HIV condition. Siegel, Raveis and Karus (1998: 686) identify wisdom in older people as an advantage in the management of HIV. The better management of HIV is seemingly due to a process of transition and transformation that one undergoes when living with HIV. Russell and Seeley (2010: 375) report that people who are living with HIV go through a transition phase in which, ultimately, they accept their condition and consider HIV as chronic and not a terminal condition, in keeping with the now widespread availability of treatment in the form of antiretroviral drugs (ARVs). Such meanings are usually created when a person remains optimistic and upbeat about the future regardless of an HIV infection (Emlet, Tozay and Raveis 2010: 5). The social construction of HIV and age therefore has a bearing on the everyday experiences of this study’s research participants.

2.4.2 Creating new meanings as people grow old with HIV

The role played by a person in organising everyday life is significant to how he or she traverses life. Part of it involves creating new meanings in the face of challenging experiences. Meanings, in relation to Hendricks’ model, involve aspects of the social world that people consider as sensible and relevant (see section 1.3.2, pg.30). Thus, as people age, they become
selective with regards to positions they can take to deal with challenges in their lifeworlds (Baars & Phillipson 2014: 3). This involves efforts that people make to understand and accept their condition as well as readjust priorities in order to live meaningful lives (Baars & Phillipson 2014: 11). New meanings may therefore be created upon realising that one is getting old (Van Willigen 2015:5) and living with HIV (Milam 2004: 2354).

Positive psychological changes, referred to as post-traumatic growth, can be constituted through the way a person living with a stressor experiences an improvement in personal characteristics as he or she goes through an adversity or personal life crises (Tedeschi & Calhoun 2004: 1). Examples of post-traumatic growth developments include a positive outlook on life, positive perception of self, personal strength, spiritual growth and an appreciation of life (Hefferon, Grealy & Mutrie 2009: 343; Sherr, Nagra, Kulubya, Catalan, Clucas & Harding 2011: 614; Joseph, Murphy & Regel 2012: 318). Hence, people may view life positively by adopting some self-enhancing changes towards what they would be struggling with. These changes include lifestyle changes, self-efficacy, inner strength, spiritual transformation, appreciation for life, compassion, establishment of meaningful social relationships, closeness to others, material gain and adjustment of priorities (Milam 2004: 2353; Tedeschi & Calhoun 2004: 1; Park & Lechner 2006: 56).

Post-traumatic growth is common within people who would have been living with HIV for quite some time and if there is a possibility to live longer through the uptake of ARVs (Milam 2004: 2358). People indeed grow positive perspectives on life, engage new and health behaviours, strengthen their relationships with friends and family and appreciate life more than they used to do when hopeful and willing to live a fuller life (Hefferon, Grealy & Mutrie 2009: 370; Joseph, Murphy & Regel 2012: 317). Those who develop such positive attributes live
with a positive mental health and lower levels of psychological distress (Tedeschi & Calhoun 2004: 13; Sawyer, Ayers & Field 2010: 443) as they focus more on positive changes. Some become more empathetic to those that are in the same condition as them (Hefferon, Grealy & Mutrie 2009: 371; Joseph, Murphy & Regel 2012: 317) and create opportunities to help each other overcome the challenges they might be facing.

Furthermore, living with HIV entails a transformation process in which one starts by individually experiencing feelings of detachment, proceeding to accepting the condition and to feeling empowered and in control of the condition and life in general (Tsarenko & Polonsky 2011: 465). Similarly, people with chronic conditions “must interpret the meaning and significance of the illness, tolerate, adjust to, and reduce negativity, maintain a positive self-image, access resources and maintain satisfying relationships with others” (Watkins-Hayes, Pittman-Gay & Beaman 2012: 2029). Such positive psychological changes are usually attributed to finding and establishing new meanings in the search for a purpose in life. This is also considered as a turning point where people make some changes in their lives and create new meanings with a sense of continuity and a reflective outlook (Ben-Ari 1995: 155). In short, some people with a chronic condition such as HIV end up rebuilding their disrupted lives by focusing on the positive things that help them to live a meaningful life. They thus create new meanings in their selection of life experiences that make sense to the conditions that they live in or with.

2.5 Typifications in the life of a person who is growing old with HIV

As noted earlier in the theory chapter, section 1.2.1.3 (pg.17), typifications are recipes or common-sense ways of doing things (Kim & Berard 2009: 265; Inglis & Thorpe 2012: 96).
Typifications are discussed here in relation to popular optional forms of treatment that some people use in managing sickness. Incidentally, there is good access to ART in Zimbabwe, yet the use of herbal remedies is equally high (Bepe, Madanhi, Mudzviti, Gavi, Maponga & Morse 2011: 48; Simmons 2011: 476) because the use of such remedies is socially, culturally and spiritually accepted (Müller & Kanfer 2011: 459; Maroyi 2013: 14). As such, people justify the use of herbs on the grounds that it is in alignment with their cultural and religious beliefs, which value traditional medicines (Müller & Kanfer 2011: 459). Thus, the use of non-allopathic ways of treating HIV can be typified in situations where processes are mastered and desired outcomes are achieved.

The meanings that people attach to illness often predict how they treat that particular illness. Some people in Africa put faith in traditional healers owing to the belief that they have the ability to point out the ultimate cause or perpetrators behind a problem and to heal the sick with natural medicine (Duffy 2005: 26; Nolen 2007: 64). The use of such treatments does not mean that a patient undervalues the Western doctors’ potential, but reflects different perspectives of health, illness and treatment that are influenced by culture (Thomas, Aggleton & Anderson 2010: 737). The motive, in most instances, will be to get rid of the supernatural evil forces that are believed to cause bad health (Littlewood & Vanable 2011: 264). In addition, some people find it rational to embrace an all-inclusive way of dealing with ailments that embraces both conventional and non-conventional means (Western, traditional and spiritual) to alleviate sickness. They acknowledge divine healing from God, traditional interventions to alleviate underlying causes, and the effectiveness of Western medicine in treating HIV symptoms and the side effects of HIV treatment. Sickness assumed to be a result of witchcraft is, therefore, presumed as alleviated by traditional means, while other illnesses are treatable with western medicine.
Furthermore, a person with HIV can adopt health promoting practices as a part of non-inherent typified actions. In older people who are living with HIV, this is arguably achieved easily, because older people often have better self-control and care for their health (Emlet, Tozay & Raveis 2010: 4). Dietary requirements, which are important in the immune response of the body, are one aspect of care. A healthy diet that promotes physical fitness and a good immune response is key to the wellbeing of a person who is living with HIV (Ivers, Cullen, Freedberg, Block, Coates, Webb & Mayer 2009: 1096). A person with HIV can therefore follow a certain diet to live a healthy life.

A person who is living with HIV can also typify certain health promoting and preventive strategies to avoid re-infection or infecting others with the virus. It is known that HIV can be transmitted through exposure to infected blood. A person living with HIV therefore must adopt practices that curtail the spread of HIV. People in Zimbabwe, for example, often share razors or re-use them for nail-cutting, shaving, circumcision, skin incisions and piercing (Brewer 2011: 183). This can lead to people spreading HIV unknowingly. Typifications in the life of a person who is living with HIV are therefore applied as strategies for survival in that a person adopts certain practices to get healthy and avoid re-infection as well as infecting others.

Antiretroviral therapy (ART) forms part of typified actions in the everyday life of a person who is living with HIV. The cure for HIV and AIDS is yet to be discovered, thus leaving ARVs as the most effective way in managing the virus as they enable people to fight HIV, become well and live longer (High 2012: 1; CDC 2013: 1). ART also transforms HIV from a fatal to a chronic and treatable condition (Rosenfeld, Ridge, and Von Lob 2014: 20) if adherence is strict. Scholars such as Nolen (2007: 114) state that ART is also regarded as a process of converting
the “dying to the living”. The fact that typifications are standard and to a great extent homogeneous, compels a person to adopt ART as prescribed.

As pointed out in discussions on theory (section 1.2.1.3, pg.19), typifications can be formed on the basis of stereotypes (Inglis & Thorpe 2012: 92) which, in the HIV context, materialise in the form of labelling and use of derogatory language (Ritzer & Goodman 2004). Social history and negative media representations of the HIV epidemic impact on the public’s perceptions about the epidemic which can result in unfair judgements, stereotypes and misinformed attitudes towards people with HIV. This dates back to the 1990s when the HIV epidemic became common in Africa and later passed on to successive generations. For example, the first cases of AIDS reported in America (CDC 1981) were associated with the labelling of the condition as a gay-male disease. HIV and AIDS therefore, became known to Zimbabwe and other parts of Africa as a gay-man-plague or GRID (Gay-related immune deficiency) (Nolen 2007: 6). Furthermore, sexual intercourse between people of the same sex is stereotypically regarded as taboo in many African societies, which means some would not disclose that they are HIV-positive for fear of homophobic-related social denigration. Some heterosexuals initially chose to ignore HIV prevention believing that it would not affect them as it was labelled a gay-male disease, while some women believed that they were safe because HIV was stereotypically confined to gay men. Such misconceptions still exist in the everyday lives of research participants as people assume that HIV is associated with a certain group of people.

The visibility of the impact of AIDS in most parts of the world resulted in the condition being given fear-inducing names. AIDS was labelled the ‘Slim’ disease in the early 1980s because of its ability to transform the figure of a person from a good physical shape to a skeletal one (Nolen 2007: 7; Merchant & Lala 2012:1507). Zimbabwe has few scientific words to describe
the HIV epidemic. As a result, terms such as ‘Mukondombera’, which means plague, or ‘Shuramatongo’, meaning the one leading to deserted dwellings are mainly used to describe HIV or AIDS (Mawadza 2004: 423) in the vernacular Shona language. The HIV infected are also labelled stereotypically as those who are on a journey towards death as people say ‘akakwira bhazi’ (one boarded a bus) or ‘go-slow’ (Mawadza 2004: 423& 428) – as in somebody who is slowly but surely going to die. Labelling and the shame-naming of the HIV epidemic is thus a common stereotypical typification in the ordinary everyday life of this study’s participants.

Songs about the HIV epidemic (Mawadza 2004: 421) also form part of the stereotypical typifications. For instance, a famous song by a Zimbabwean musician called Leonard Zhakata, alleges that women are responsible for the spread of HIV. Zhakata, in the song “Poison,” sings that HIV was poured in the female genitals and no one will survive. People in general are thus socialised to blame women for the spread of HIV, with women probably blaming and shaming themselves for the spread of HIV after internalising the meaning of the above-noted lyrics. Stereotypes in this case, shape the social world by creating images in people’s minds that are judgemental, labelling and scornful of people living with HIV.

2.6 Lived experiences of older women with HIV

Theory suggests that lived experiences involve everyday life as we live, maintain, renew, reconstruct and transform it (see section 1.2.2, pg.20). Thus, the focus of this study is on women’s everyday experiences as they live, maintain, renew, reconstruct and transform their life in the process of ageing with HIV. It is documented that experiences of older women are influenced mainly by entrenched social and cultural factors that influence the physical,
emotional and social being of a person (Kaya 1999: 40; Davidson, Digiacomo & McGrath 2011: 1034; High 2012: 2). Getting old, regardless of HIV, is a challenge which can impact on a woman’s quality of life. Generally, older women face challenges in accessing quality healthcare, owing to poverty and poorer health (WHO 2007: 18-19). On the whole, older women have particular requirements and concerns related to their age and this becomes complicated when they are living with HIV. The following sub-sections discuss aspects of the lived experiences of women who are growing old with HIV.

2.6.1 Social life in older people

I review literature on the social life of older people in an attempt to understand the lived experiences of the research participants. Generally, a high morale and satisfaction with life is achieved through meaningful social interactions. As a result, social networks, which form part of a person’s life, impact on the everyday experiences of people. Older people are prone to loneliness as their social life becomes less active with age (Wrzus, Hänel, Wagner & Neyer 2013: 53). Their few and fragile social networks can be attributed to losing family members and friends due to death, divorce and separation (Kaya 1999: 40; Emlet, Gusz, & Dumont 2003: 46; Makiwane, Ndinda & Botsis 2012: 15). As such, older people have limited platforms to share their concerns about HIV and ageing and may also choose not to share their concerns due to fear of straining the remaining few social networks they have (Emlet et al. 2003: 46). Other scholars including Luong, Charles and Fingerman (2010: 5) suggest that social relationships get better with age as people acquire greater satisfaction through being socially adept. Therefore, the social life of older people has a bearing on their everyday experiences as it either makes life meaningful or insignificant.
2.6.2 HIV and the family

The research participants’ lived experiences are also explored in relation to their familial ties. A good relationship with family is one of the social relationships that are linked to a healthy and quality life as well as the general well-being of a person with HIV (Mitchell, Chaboyer, Burmeister & Foster 2009: 549; Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter & Chassany 2012: 501). Usually, there is a platform within the family to exchange resources, such as money, food, warmth and emotional sustenance, which are basic to life (Moss 2002: 652 & 655). Such things are significant in everyday life especially in times of sickness or other challenges brought about by age. The Zimbabwean virtues of ‘Ubuntu’ encourage collective responsibility where no one person is able or expected to single-handedly overcome the challenges of life (Mandova & Chingombe 2013: 101).

The 2012 Zimbabwe Demographic and Health survey shows that 95% of people are willing to take care of a sick HIV infected family member (ZIMSTAT 2012: 188). This reflects respect for traditional societal virtues such as kindness and humility that honour and preserve life. This makes those who are not well feel comfortable, loved and socially accepted even where problematic HIV-related symptoms exist (Duracinsky et al. 2012: 501). Those family members’ performance of acts of love towards the sick enables the family members’ experience of reduced levels of disease-related anxiety and the constitution of improved coping strategies (Mitchell et al. 2009: 550). Therefore, those who receive care, as well as those who provide it can have an opportunity to value each other and strengthen relationships (Hefferon, Grealy & Mutrie 2009: 371; Joseph, Murphy & Regel 2012: 317).
Families are usually brought together by an illness and find ways to support each other as well as pull through difficulties brought about by the sickness afflicting one of their own (Gilbert & Walker 2010: 143). In some instances families work together towards providing the care and support, finding the necessary treatment, and facilitating the care services for the infected person. Some people with HIV and AIDS maintain a good treatment adherence through the support of their families (Bhat, Ramburuth, Singh, Titi, Antony, Chiya, Irusen, Mtyapi, Mofoka, Zibeke, Chere-Sao, Gwadiso, Sethathi, Mbondwana & Msengana 2010: 950; Patel, Ratner, Gore-Felton, Kadzirange, Woelk & Katzenstein 2012: 358). The case of one of Stephanie Nolen’s research participants in 28 stories of AIDS in Africa, in which the family came together and arranged that an exiled sick person be brought home to get the necessary treatment (Nolen 2007: 81) is a significant example. In that narrative, some family members went on further to gather as much information as possible about HIV so that they could help their sick family member. Kaya (1999: 43) views such support as a way of turning negativity into positivity as people convert fear, rejection and uncertainty into hope, acceptance and confidence. The relationship between a woman with HIV and her family is therefore crucial in her lived experience and offers a better understanding on how families interact in times of sickness.

Nevertheless, there are reports that suggest otherwise. Gilbert and Walker (2010: 143) report that families can play a negative role in the life of a person who is living with HIV. This is because some family members may feel embarrassed and not want to associate with people who have such a stigmatised condition (Gilbert & Walker 2010: 143). That is why some people prefer to keep the HIV-positive status of their family members private (Sambisa, Curtis & Mishra 2010: 172; ZIMSTAT 2012: 189). The less supportive family members feel ashamed of being identified with a person who is known or suspected of suffering from HIV-related
diseases. On the whole, families are crucial in shaping lived experiences since familial relations can act as crucial support systems in situations where life is disrupted by sickness.

2.6.3 The physiological needs of older women with HIV

The physiological needs of a woman who is ageing with HIV also form part of her lived experiences. These physiological needs impact on the way she ages and lives with HIV because both are crucial to human survival and the proper functioning of the body. Older women fall under the poorest people in society in most parts of the world (Emlet, Tangenberg & Siverson 2002: 237; Barrientos, Gorman & Heslop 2003: 558). Unlike in other countries, the government of Zimbabwe does not provide for later life social and economic support, such as old age grants, for the elderly. Therefore, older people in Zimbabwe may face challenges in meeting both their physiological needs and those of people under their care.

The failure to meet the physiological needs of people is likely to lead to these people living in poverty. It is known that poverty is a social determinant of HIV infection (Shisana, Rice, Zungu & Zuma 2010: 39). It is also equally known that HIV is a determinant of poverty because it leads to reduced productivity and dwindling income (Ivers, Cullen, Freedberg, Block, Coates, Webb & Mayer 2009: 1096). The interplay between HIV and poverty creates a vicious cycle that worsens the severity of each condition with the effects of HIV likely to pose barriers to the acquisition of the necessary requirements for living at individual, household and community levels (Weiser, Young, Cohen, Kushel, Tsai, Tien, Hatcher, Frongillo & Bangsberg 2011: 1729). Furthermore, the effects of age on the physique of a person can undermine that person’s capability to provide for themselves sufficiently. However, where needs are met, life can be lived with limited disruptions because, a healthy looking HIV-
positive person is likely to experience less discrimination than a mal-nourished one, who attracts attention for being thin, which is a marker for HIV stigma.

2.6.4 Social roles and everyday activities

Lived experiences also include the social roles that people perform in their everyday life. The social roles refer to responsibilities, behaviours, expectations, rights and beliefs of a person occupying a social category such as being a mother, relative, grandmother, friend, spouse, worker or homemaker (Plach, Stevens & Heidrich 2006: 61). Although some studies report good functional ability among older women (Nyirenda, Chatterji, Falkingham, Mutevedzi, Hosegood, Evandrou, Kowal & Newell 2012: 263; Schatz & Gilbert 2014: 778), those with a compromised health experience reduced capacity for carrying out some chores that are necessary or expected of them (Schatz & Gilbert 2012: 16). One qualitative study which explored the challenges faced by older women who are living with HIV in performing their daily tasks reports that the women complain of poor age-related physical and mental health (Schatz & Gilbert 2014: 778). These include pain, fatigue, stress and depression, with some studies suggesting that lack of, inadequate or poor quality of physical and mental activities often have an impact on older women’s psychological wellbeing (Plach, Stevens & Heidrich 2006: 62; Sun, De Florio, Gui & Blondia 2014: 5). Therefore, encountering difficulties in fulfilling everyday tasks impacts on older people’s existential being as their emotions get affected.

Depending on the level of support that one gets, a person can manage to carry out everyday activities with limited capacity while facing minimal challenges. It is possible for some older people to carry out their daily activities with minimum trouble despite their compromised
physical and mental health. This is made possible because some practice health seeking behaviours or get support from other family members. As reported in the Schatz and Gilbert’s (2014: 778) study, some older people get help from their children and grandchildren who take over some of their roles.

Poku (2005: 99) points out that the burden of care lies primarily on women. In contexts such as those of my Zimbabwean participants, women’s acceptance of the fulfilment of normative gender roles indicates that they accept the responsibility of being primary care providers within families (Muller 2005: 53). Most women usually take on this role with limited support (Poku 2005: 100) and in most cases, inadequate resources (Lee, Li, Jiraphongsa & Rotheram-Borus 2010: 58). They shoulder that role as part of the family’s unpaid work and as a socially-accepted gendered norm within their society. Caring for others thus comes naturally to most women in these contexts in which they are highly likely to put others, such as children and spouses, first. As Mayers, Naples and Nilsen (2005: 93) report, women often do this at the expense of their own needs.

There are instances however, where older women face expanded roles of care as they live with compromised health and limited resources. Situations can oblige them to live as a patient and a carer at the same time (Mayers et al. 2005: 94). The HIV epidemic has resulted in children being orphaned and left in the care of older people or grandparents. As a result, grandparents engage in long-term commitments of care for their children as well as their grandchildren (Munthree & Maharaj 2010: 155) instead of living as socially-expected cared-for-elders (Schatz & Gilbert 2014: 782). At some point, approximately 70% of older Zimbabwean women (sixty years and above) were caring for children that had been orphaned due to HIV and AIDS (Poku 2005: 92). Such responsibilities and expanded roles are arguably a cause of
physical and mental exhaustion in older people (Munthree & Maharaj 2010: 171) with some arguing that caregiving in itself, despite old age, is stressful and straining (Lee et al. 2010: 58). Lived experiences in this context, therefore include people’s social life, relations with family, physical needs and the roles that society expects people to perform.

2.7 Intersubjectivity and disclosure of HIV status

Intersubjectivity, a concept discussed in the theory chapter (see section 1.2.3, pg.21), concerns people’s experiences as they connect with each other and co-create their reality and the meanings thereof. The disclosure of one’s HIV-positive status is dependent on the nature of people’s interactions. Usually, disclosure is a difficult decision to take because HIV can evoke criticism, ridicule and a breakdown in relationships (Ben-Ari 1995: 160), especially when the person being disclosed to is judgemental and unsympathetic.

Fear of, or perceived, stigma often influences the nature of disclosure of one’s HIV-positive status (Gilbert & Walker 2010: 143) with some believing that they become outcasts in society if they are known to be living with HIV (Nolen 2007: 26). As a result, some choose restricted disclosure (partially-open or limited) or non-disclosure (Rodkjaer, Sodemann, Ostergaard & Lomborg 2011: 3; Stutterheim, Bos, Pryor, Brands, Liebregts & Schaalmam 2011: 382). Others however, decide to take full or open disclosure whereby they tell everyone of their condition without fear or concern of public reaction. They would have reached a high level of understanding and tolerance that is usually constituted when a person lives longer with HIV or develops competencies to deal constructively with any negative reactions. Ben-Ari (1995: 160) brings to light another perspective on disclosure by stating that some people disclose their conditions because they want to realise opportunities for “mutual support and caring” from the
targeted recipients. In this case, relationships are natured positively with less or no criticism and ridicule. This makes the disclosure of one’s HIV status an intersubjective activity that depends on how people connect with each other.

Studies have shown that women with HIV/AIDS deal with various forms of suffering owing to the disclosure of their HIV-positive status. It has been noted that women often fear rejection by family, domestic violence and possible collapse of their relationships after disclosing their HIV-positive status (Kasenga, Hurtig & Emmelin 2010: 33; Anglewicz & Chintsanya 2011: 1002; Turan, Bukusi, Onono, Holzemer, Miller & Cohen 2011: 1111). People may therefore find it difficult to live openly and positively with HIV owing to fears of alienation and violence (Rodkjaer et al. 2011: 3).

In addition, disclosure of HIV status, in most African societies, is culturally determined as reported by Donahue, Dube, Dow, Umar and Van Rie (2012:1237) who suggest that some contexts and cultures influence disclosure. People can be forced to tell others that they have HIV because of existing traditions related to sickness. In Zimbabwe, custom dictates that a person with a serious ailment should inform her family. Nevertheless, the seriousness of an illness often forces people to disclose their HIV status (involuntary disclosure), especially in cases where a person gets so ill that he or she needs all kinds of support to pull through (Gilbert & Walker 2010: 143) or where visible physical symptoms appear (Stutterheim et al. 2011: 389).

Emlet, Tangenberg and Siverson (2002: 237) point out that older people with HIV might feel ashamed and humiliated to disclose their HIV status to their adult children, siblings and other family members. Some married women may also feel ashamed and assume that people would
presume that they acquired HIV because they (and not their husbands) were promiscuous — a breach of a socially desirable and accepted African gender norm where women are supposed to be faithful to their husbands (Turan et al. 2011: 1118). Thus, people’s decisions to disclose or not to disclose their HIV status is mainly intersubjective depending on: how society perceives the condition, how people engage each other, culture-related tradition, and the state of physical health of a person.

2.8 Existential phenomenological experiences of older women with HIV

Existential issues, as discussed in section 1.4 of the theory chapter (see pg.31), involve people’s experiences, their feelings and emotions as they try to find meanings in life. Experiencing a shock and a challenge, such as an HIV-positive diagnosis, often heralds a contemplation of life’s importance, purpose and meaning (Milam 2004: 2354). Some people may follow an HIV diagnosis with asking themselves questions such as: “What am I going to do in my life?” (Kremer, Ironson & Kaplan 2009: 368). Others develop excessive anxiety that can lead to suicidal thoughts (Capron, Gonzalez, Parent, Zvolensky & Schmidt 2012: 301). Thus, most people produce negative portrayals of themselves (Calhoun, Cann, Tedeschi & McMillan 2000: 526). This often intensifies their vulnerability to psychological problems (Gibson, Rueda, Rourke, Bekele, Gardner, Fenta & Hart and the OHTN Cohort Study 2011: 371).

The news of an HIV-positive diagnosis is described as a traumatic stressor that brings along psychological distress (Nightingale, Sher & Hansen 2010: 452; Sawyer, Ayers & Field 2010: 436). The diagnosis may be unexpected with the condition itself being life-long and life-threatening (Sawyer et al. 2010: 437). As a result, people may feel as if they would be living a foreshortened life with death an imminent reality (Mayers, Naples & Nilsen 2005: 94).
Common responses that emerge in analysing existential issues in people who are living with HIV are: disbelief, denial, guilt, anger, sorrow, pain, frustration, anxiety, uncertainty, fear, helplessness, worthlessness, loss of internal control, low self-esteem, loss of interest in things, stress and depression (Mayers et al. 2005: 93; Kremer et al. 2009: 368; Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter & Chassany 2012: 501). In addition, people may experience behavioural shock reactions such as crying, anger, withdrawal, self-denigration, impulsiveness and bodily checking for any signs of physical deterioration (Miller 1987: 23). For some however, a positive HIV-diagnosis brings relief at knowing the cause of illnesses that one is encountering or has been troubled by (Kasenga, Hurtig & Emmelin 2010: 32). They embrace HIV with some degree of positivity that is significant in restructuring life meaningfully. These existential mind states are common when people face a life-changing experience like an HIV-positive diagnosis and may be exacerbated by the realisation by the same people that they are also not getting any younger.

2.8.1 Coping with HIV

Coping with HIV and its physical and social consequences is one of the phenomenological existential aspects in the experiences of people with HIV. Coping, as tactics that people deploy in dealing with a problematic condition, involves mechanisms (inborn or acquired behaviours) which operate through processes and personality traits in an attempt to influence how HIV is managed (McIntosh & Rosselli 2012: 2145). Ideally, difficult transitions or changes in one’s life compel people to engage with a stressor (Varni, Miller, McCuin & Solomon 2012: 130) in order to achieve significant solutions that restore social order. I discuss some of the adaptive and mal-adaptive coping mechanisms that people employ in dealing with HIV in the following sub-sections.
2.8.1.1 Social support

Social support is considered as one of the adaptive coping mechanisms where resources are exchanged to increase people’s wellbeing (van Dam, van der Horst, Knoops, Ryckman, Crebolder & van der Bart 2005: 2). Social support is multidimensional and involves emotional, network, tangible, instrumental and information support (Sarafian 2012: 668; Wilcox & Vernberg 2013: 5). It also includes the involvement of family members, friends and others sharing the same situation (van Dam et al. 2005: 2). Other means including increased socialisation and supportive relationships assist people to cope with HIV (Knowlton, Curry, Hua & Wissow 2009: 526; McIntosh & Rosselli 2012: 2147; McDoom, Bokhour, Sullivan & Drainoni 2015: 98). Therefore, social support is crucial in the management of any challenging condition that a person experiences.

2.8.1.2 Religion

The link between religion and health shows that certain religious practices, including prayer, are beneficial and have positive health outcomes (Trevino, Pargament, Cotton, Leonard, Hahn, Caprini-Faigin & Tsevat 2010: 386 & 387; Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter & Chassany 2012: 502). Trevino and associates report a close association between religion-oriented coping and high levels of self-esteem and spiritual well-being among people living with HIV (Trevino et al. 2010: 386). Religion can take the form of traditional cultural practices (Shoko 2013: 33) or that of Western forms such as Christianity in which prayer is used to address stressful conditions like HIV (Peltzer, Friend-du Preez, Ramlagan, Fomundam & Anderson 2010: 126). As such, religious people can cope
well with HIV if they believe that their prayers and other practices are effective in sustaining them.

### 2.8.1.3 Hope and optimism

Hope is one of the adaptive emotion-focused coping strategies that can bring improved functioning. Some of the people living with challenging conditions, such as HIV, express a positive outlook in life and continue living with a positive attitude. This, in relation to this study, reflects a positive outlook on ageing with HIV by “maintaining future mindedness, feeling upbeat about life, and remaining hopeful about one’s continued well-being” (Emlet, Tozay & Raveis 2010: 5). Using ARVs and experiencing its positive outcomes often adds hope to people with HIV because it helps them to fight the virus, feel better, and curtail its debilitating course. It also gives them strength to face each day and stimulates positive attitudes to living with HIV. Therefore, the hope that the infected pin on HIV medication in believing that it works, and will continue to do so, acts as a coping strategy.

### 2.8.1.4 Accepting being HIV-positive

It is documented that a person living with HIV eventually reaches a turning point and learns to incorporate an HIV condition into their sense of self (Baumgartner & David 2009: 1730). Russell and Seeley (2010: 375) describe it as an evolution in living with HIV whereby people change their perceptions from being HIV-positive to being positive about HIV. In this case a person accepts his or her positive HIV status and treats it as any other chronic condition, rather than viewing it as a terminal illness. Although Russell and Seeley’s study documents turning points that people with HIV reach after initiating ART, they also point out that there are factors
in the social environment that enable people to adopt such a transition (Russell & Seeley 2010: 382). Nevertheless, accepting one’s HIV-positive status is achieved by both social and medical enablers.

### 2.8.1.5 Mal-adaptive coping

Some people adopt mechanisms that are detrimental to their wellbeing, which are referred to as maladaptive coping mechanisms. These are often employed during people’s struggle to accept that they are HIV-positive and are arguably associated with poor health outcomes (Mo & Coulson 2012: 445). Maladaptive coping strategies include avoidance, distancing and self-imposed social isolation (McIntosh & Rosselli 2012: 2147). In this case, no effective action is taken to address the underlying problem because people are so worried about the public’s reaction towards their condition. The more the condition is left unattended, the more the deterioration, and the more one is likely to be socially isolated by those who do not empathise with that person. Hence, the mentioned mal-adaptive coping strategies are counter-productive to the social, physical and mental wellbeing of persons living with HIV.

To sum up, existential issues mainly involve feelings and emotions associated with HIV. Generally, there is psychological distress as a result of an unexpected and feared condition. It is noted that emotions or reactions to living with HIV determine whether one can adapt and employ positive coping strategies or adopts mal-adaptive coping mechanisms.
2.9 Gender and the experiences of older women with HIV

Generally, gender refers to biological, social and personal factors related to roles, behaviours, responsibilities and expectations associated with being a woman or a man (Lindsey 1997: 2; Carl 2012: 26). Gender is seen as a product of learnt or adopted social forces that establish the normative context within which one acts and reacts (Wharton 2005: 54; Holmes 2007: 42). Hence, gender is characteristic of “expected attitudes and behaviours which a society associates with each sex” (Lindsey 1997: 3). Interactions are therefore judged on the maleness and femaleness of a person that people internalise through social interaction (Muller 2005: 31&42). Gender differences and inequalities in society are thus largely revealed through the way society expects women to carry themselves differently from men, and vice versa. Such social forces are a source of certain vulnerabilities for those regarded as being of lower or lesser status in society (Baylies 2002: 3). Gender-related experiences of women are discussed in the following sub-sections:

2.9.1 Gender inequality and HIV vulnerability

In the light of the forgoing, it is important that I discuss the inequalities that are embedded in gender disparities since vulnerability to HIV infection is largely socially driven by gender inequality (Higgins, Hoffman & Dworkin 2010: 436; UNAIDS 2014: 4). I thus discuss how gender inequality impacts on the experiences of women as they are the main focus of this study.

Gender inequality emanates mostly from men viewing themselves as more powerful than women, a view that is naturalised in many patriarchal societies, resulting in men being assigned a superior status over women (Muller 2005: 31). The superiority of men often affords them
positions of power which may confine women to the category of owned-beings (Shoko 2013: 19). Men in the ‘traditional African’ settings, according to Jack and Ali (2010: 5), tell “women who they are” and what they are “supposed to be like”. Most women, by default, are awarded a low status and therefore disempowered. In addition, such conditions lead to the creation of and belief in oversimplified notions about men’s sexual behaviour. There is literature that suggests that realistically, men have greater control over sexual encounters and expect their female partners to comply to these conditions with passiveness as mentioned in Nolen (2007: 65) and Shoko (2013: 21).

Heterosexual relationships are a platform for unequal power relations where women’s sexuality and behaviour are systematically controlled by men resulting in non-volitional sexual encounters at the expense of women’s health (Higgins, Hoffman & Dworkin 2010: 436). Women are already more vulnerable to HIV-infection because of their biological make-up, but their vulnerability to HIV infection becomes even higher because they lose their voice over sexual matters (Muller 2003: 24; Shisana, Rice, Zungu & Zuma 2010: 39; Auerbach, Parkhurst & Cáceres 2011: S293). Men consequently get an upper hand from the androcentric sexual interactions that are male-centred and favour them (Lindsey 1997: 2) or they feel the pressure to act according to what is expected of them in their patriarchal societies, which in this case is dominance over sexual issues.

Gender inequality that favours men also renders women more vulnerable to sexual abuse and violence as well as socioeconomic factors that lead them into prostitution and unsafe sexual relationships (Kaya 1999: 40). All this impacts on how women manage their HIV condition. For instance, where women are economically dependent on men, they feel powerless and likely to get medical help only if men pay for it. Others, upon receiving an HIV-positive diagnosis,
are afraid to inform their sexual partners for fear of abuse even when it is likely that they got infected by that particular partner (Kaya 1999: 43). HIV-positive diagnosed women are also likely to get stigmatised more than men (Sambisa, Curtis & Mishra 2010: 172). Women’s gender-related experiences are thus impacted by inequalities that exist in a society where social categories assigned to men and women define who is superior to another.

A compounding factor is that it is socially acceptable in Zimbabwe for men to have multiple sexual partners in the form of girlfriends or wives (Shoko 2013: 19). Globally, masculinity is socially and culturally associated with risky behaviour like multiple sexual partnerships as argued by (Muller 2005: 24; Higgins et al. 2010: 437). Men’s sexual ‘adventures’ are normalised to the extent that they perceive sex as obligatory and that it is a man’s nature to prove and exercise his manhood (Muller 2005: 34; Shoko 2013: 2). Manicaland, the province in which the participants of the study live, is among the Zimbabwean provinces that reported the highest number of men with more than one sexual partner − 4.7 sexual partners per person (ZIMSTAT 2012: 193-194). Therefore, the context within which research participants live is an environment where multiple sexual partnership is naturalised and accepted as a reality.

High levels (98%) of knowledge about HIV among Zimbabwean women, are recorded in a 2012 national Zimbabwe survey (ZIMSTAT 2012: 180) but culture and gender roles often make it difficult for women to translate knowledge into action. Women, though knowledgeable, still lack the tenacity and assertiveness to refuse risky and unsafe sexual practices (ZIMMSTAT 2012: 189) because society accords them a passive position in sexual issues. Some silence themselves for fear of losing the sexual relationships they have, and to prevent conflict and abuse (Jack & Ali 2010: 5). Some women who are already infected with HIV and have been exposed to health-promoting practices, may become empowered to make
and keep firm decisions associated with positive health outcomes (DeMarco 2010: 348). In addition, sexual behaviour is not equally related to knowledge or education level (Baden & Wach 1998: 10). Therefore, even knowledgeable and educated women may lack the boldness to transfer knowledge into action, especially when they internalise the inferior status they are accorded in society.

2.9.2 Marriage and HIV

Marriage and gender are interconnected because they both reveal imbalances in heterosexual relationships. Marriage arguably has negative health implications and is identified as the major risk factor for HIV infection among African women (Higgins, Hoffman & Dworkin 2010: 436) because the prevention of HIV can be difficult or impossible (Duffy 2005: 28). Some married women develop a “false sense of security” and consider themselves at low risk of contracting HIV (Nolen 2007: 69). Yet it is reported that marriages in Africa have a high HIV risk (Higgins et al. 2010: 436; Mbona 2012: 9).

In trying to understand barriers to safer sexual practices among married women in Zimbabwe, Mugweni, Omar and Pearson (2015: 388) report individual, relational and community-level barriers to safer sex. The individual barriers include lack of assertiveness to negotiate safer sex, in which women cannot freely express their concerns and needs, just as they cannot refuse sex with their husbands or question men’s sexual behaviour (Duffy 2005: 27; Mugweni et al. 2015: 390). Relational barriers include trust in marriages where partners expect each one of them to be faithful to each other. Community barriers involve influences from extended family and religious groups which encourage women to be submissive to their husbands (Bassett & Mhloyi 1991: 143). In addition, a married woman is expected to remain loyal and faithful to
her husband in order to escape violent confrontations or heavy social sanctions that come with extramarital affairs or divorce for married women (Duffy 2005: 24). A woman’s social status is usually measured by her success in marriage and as such divorce is socially unacceptable in the Zimbabwean context (Mugweni et al. 2015: 394). These dynamics related to marriage shed light on how women’s experiences can be gendered.

Married women are highly likely to trust their matrimonial relationships and comply highly with societal expectations of fidelity norms (Baylies 2002: 11; Higgins et al. 2010: 436). They are less likely to worry about safer sexual practices, yet, married men are likely to have unsafe sexual encounters outside marriage (Baylies 2002: 11). Studies have shown that in Zimbabwe, condom use in marriage is very low (Wyrod, Fritz, Woelk, Jain, Kellogg, Chirowodza, Makumbe & McFarland 2011: 1281). Condom use is considered applicable in transactional sexual encounters and any demand to use them in a marriage implies mistrust (Chirawu 2006: 34). The bride-price that men pay can be argued to be one of the causes. In order to authenticate a marriage in most African societies, a man pays bride-price as compensation to the wife’s family (Chirawu 2006: 35). Most women even adopt the husband’s name upon marriage (Shoko 2013: 32). By so doing, the husband claims guardianship of a woman and creates a social form of security in line with tradition and societal expectations where men are ‘keepers’ of women (Nxumalo 1999: 59). Thereafter, the wife belongs to the man and his family, such that even after the husband dies, his brother can inherit the wife to keep her within the clan (Chirawu 2006: 37). Prisca Mhlolo’s account of life with HIV in Stephanie Nolen’s 28 stories of AIDS in Africa shows how her husband threatened and reminded her that he is in charge of her because he paid lobola (Nolen 2007: 60). Relationships, in this case, are bound to be power based and unequal, with men occupying a superior position.
2.9.3 Women and HIV-related stereotypes

Gender-related stereotypes are common in society. Stereotypes are defined by Earnshaw, Smith, Chaudoir, Lee and Copenhaver (2012: 2) as “group-based beliefs about people living with HIV (PLWH) that are often applied to individuals”. HIV is mostly blamed on women especially if they are the first in a sexual relationship to test HIV-positive. They are almost mythically regarded as HIV vectors that transmit the virus to their babies and partners (Baylies 2002: 3). Some people in Zimbabwe even refer to, and stigmatise HIV and AIDS as a women’s disease (Mawadza 2004: 429). Women are also likely to be blamed for the husband’s errand ways or adultery. If a man engages other women for sexual relationships, people assume that the woman is failing to play her sexual roles satisfactorily or she has failed to control her man’s sexual desires (Chirawu 2006: 32). Traditionally, some people believe that a wife must use traditional medicine to control the sexual cravings of her husband in what is commonly known in Zimbabwe as ‘kupfuhwira’ (Chirawu 2006: 32).

Furthermore, HIV, just like other sexually transmitted infections, is associated with female prostitution (East, Jackson, O’Brien & Peters 2012: 15). Some call the HIV epidemic a ‘prostitute’s’ disease (Woudenberg 1998: 9; Mawadza 2004: 430). This assumption stems mainly from the historical links between sexually transmitted infections and prostitution (East et al. 2012: 16) as well as previous cases of HIV among truck drivers who had sex with female prostitutes (Muller 2005:37; Nolen 2007: 10). Even early prevention programmes concentrated on encouraging men to reduce the number of female sex partners (Bolton 1992: 145; Nolen 2007: 69) — implying that they get HIV from female prostitutes. This encourages the stigmatisation of women living with HIV as they are seen as prostitutes who instigate the HIV epidemic (Muller 2005: 37) and portrays men as victims (East et al. 2012: 16). Some people
fail to understand that a woman can contract HIV through her husband’s undesirable behaviour and the result of a man’s unsafe sexual encounters (Higgins, Hoffman & Dworkin 2010: 436). Therefore, relationship imbalances in heterosexual relationships expose the extent to which women’s experiences are gender-influenced — a reality that many societies naturalise in the favour of men who are accorded a superior social status.

In conclusion, the reviewed literature gives a better understanding of the experiences of research participants in this study. Aspects from the theory chapter are integrated into this chapter to give focus to the study. As such, the reviewed literature elaborate on the experiences related to the theories that underpin this study, which are phenomenology, the social construction of reality, existential phenomenology and gender.
CHAPTER 3 — METHODOLOGICAL ACCOUNT

The chapter discusses the methodological aspects of this study. In this regard, I follow Van Manen’s (1990: 27) and Braun and Clarke’s (2013: 31) view that a research methodology provides a framework within which the research is conducted. I touch on the philosophical underpinnings of the study and delineate how qualitative inquiry serves as an appropriate methodological approach. The research design, selection of participants, data collection and analysis, issues of credibility and ethical considerations are also described in this chapter.

3.1 Research design

This is a basic, non-experimental and descriptive form of research seeking to explore women’s narratives in order to understand their experiences of ageing with HIV. The study employs a qualitative approach in order to acquire “meaning in context” (Merriam 2014: 2) by asking the ‘what?’, ‘why?’ and ‘how?’ aspects of experience (Ritchie, Lewis, Nicholls & Ormston 2013: 3). In this way, I explore the underlying details, perspectives and insights on the experience of ageing with HIV.

Qualitative studies fit well when a researcher seeks to reveal knowledge or an understanding of the nature of reality about a social phenomenon (Merriam 2014: 3) by exploring people’s lived worlds (Brinkmann 2012: 3). The main goal of a qualitative study is to collect and construct knowledge (Brinkmann & Kvale 2015: 57), while analysing and understanding human experiences (Flick 2008: ix; Stanley & Temple 2012: 275; Braun & Clarke 2013: 24; Creswell 2013: 4). I use interviews as a tool to generate information (Briggs 2007: 552) and
to unpack meanings (Braun & Clarke 2013: 24) around the research participants’ experiences in an attempt to understand their world from their perspectives (Brinkmann & Kvale 2015: 3).

Interviews as a way of obtaining data, try to answer the most important question in epistemology which is: “How do we know whatever we know?” (Webster & Mertova 2007: 5). Interviewees are also the most important source of information, knowledge, opinions and experience (Gubrium & Holstein 2012: 32). Thus, I employ interviews in an attempt to extract details about the interviewees’ experiences, actions, emotions and their multiple perspectives on the social reality within which they find themselves (Denzin & Lincoln 2011: 3; Gubrium & Holstein 2012: 31; Johnson & Rowlands 2012: 101). Hence, qualitative inquiry is the most appropriate research design for a study in which the participants’ stories about their experiences and views of the world are the points of departure to my understanding of the phenomenon of women ageing with HIV.

3.2 Situating my study within the philosophical and theoretical paradigms that underpin qualitative inquiry

In chapter one I discussed the theoretical foundations on which this research project is based. Theories act as underlying contexts for a study (Merriam 2014: 2) and are significant in generating knowledge (Brinkmann 2012: 19). Brinkmann (2012: 6) also explains that a qualitative inquiry must be based on theoretical reflections to give it direction and rigour. Jacobsen (2009: 17) asserts further that theories and philosophies give research substance in order to avoid the research appearing as a “trivial recounting of our quotidian activities”. Thus, theory and philosophical assumptions play a key role in shaping the formulation of the research
problem, the basic research questions and the methods that are used to seek answers in a study (Creswell 2013: 18). Both theory and philosophical assumptions also act as sources of a priori knowledge in our understanding of the issues under study. Therefore, I use theories and philosophical assumptions to form a framework that guides this research.

This study employs an interpretive approach as outlined in chapter 1 (see section 1.1, pg.7). Interpretive research goes hand-in-hand with qualitative research (Merriam 2014: 8) because it focuses on the interpretation of individualised and contextualised experiences (Josselson & Lieblich 1995: ix). Interpretive research often employs a practical stance (Neuman 2000: 71) where researchers aim to understand a phenomenon or the nature of reality through what the narrator perceives it to be (Babbie & Mouton 2001: 28; Braun & Clarke 2013: 24). Since people are active agents in the social world, their narratives give insights into how they interact with the world and how the world interacts with them (Riessman 2008: 22). People understand their lifeworld by interpreting, creating and giving meaning, as well as justifying and rationalising their actions (Babbie & Mouton 2001: 28). Hence, narratives enable researchers and participants to understand and make sense of things (Josselson 1995: 32). The research participants narrate their stories through open-ended questions, as is expected in an interpretive study, which encourages participants to talk freely about their personal experiences and probe their experiences of ageing with HIV.

In chapter one, section 1.2, I also elaborate on how phenomenology as a theoretical context explores the way reality appears to people through their experiences. Phenomenology is embedded within the interpretive framework where people describe and interpret a phenomenon as it is experienced. My interviews are anchored on phenomenological assumptions with a focus on “lived space, lived body, lived time, and lived relations” (Finlay
2012: 17). In addition, phenomenology is centred on the “transitory nature of human experience” (Seidman 2013: 16) where experiences keep changing. Hence, the data gathered in this study relates to descriptions of how life was before the participants contracted HIV, how life is now, and how it will be for the women who are in the process of growing old with HIV.

My interview questions, which presuppose that experiences can be subjective (Schutz 1967: 20) and intersubjective (Riessman 2008: 22), focus on issues such as the participants’ reactions to what people do or say about them with regard to their condition.

### 3.3 Aim and objectives of the study

The aim of this study is to contribute to better and more nuanced understandings of everyday life, as experienced by older women who are growing old with HIV in the Manicaland Province of Zimbabwe. The objectives of the research are formulated in an attempt to fulfil one of the aims of qualitative research, which is to understand the ways in which people conduct and make meaning of their lives (Brinkmann 2012: 20). The research objectives are:

- To explore how women create meaning of their everyday experiences as they negotiate living with HIV whilst ageing.
- To analyse the extent to which society’s portrayals of HIV influence the subjective thoughts and actions of research participants — especially how they deal with stigmas attached to HIV.
- To identify and explore specific issues that emerge with regard to women’s experiences of ageing with HIV.
3.4 Research questions

The focus is on women from the Manicaland Province in Zimbabwe, who are growing old with HIV and between fifty and sixty-five years of age. The interpretive nature of this research project informs how the research questions are formulated. I formulate ‘episteme’ or knowledge-seeking questions because one of the main goals of a phenomenological approach is to generate knowledge (Brinkmann 2013: 90). The research questions are framed in a way that warrants qualitative inquiry because they ask for the “how?” and “what?” part of human experience. The following research questions guide this research:

- How do women create meaning of their everyday experiences as they negotiate living with HIV whilst ageing?
- To what extent does society’s portrayal of HIV influence the subjective thoughts and actions of research participants especially in terms of how they deal with stigmas attached to HIV?
- Which specific issues emerge from women’s experiences of ageing with HIV can be identified?

3.5 Research area

The Manicaland Province, one of the nine provinces in Zimbabwe, is located in the eastern part of Zimbabwe where it borders with Mozambique, as shown on the map below. Mutare, where the research participants are from, is one of the ten districts in the province that is mainly populated by the Shona cultural group (Osika, Altman, Ekbladh, Katz, Nguyen, Williamson & Tapera 2010: 7). The Mutare District is divided into rural and urban areas with the city of Mutare covering the greater part of the urban district.
Zimbabwe gained its independence from colonial rule in 1980 and established a strong health system (Osika et al. 2010: 7) which tried to embrace everyone regardless of their ethnic group (Poverty Reduction Forum Trust 2011: 8). However, the economic decline that started in the late 1990s affected the health system negatively with most health facilities operating at a very limited capacity (Osika et al. 2010: 9). This in turn hampered effective HIV prevention, treatment and care services (Campbell, Skovdal, Mupambireyi, Madanhire, Nyamukapa, Gregson 2012: 125). However, access to HIV services improved greatly by 2012 mainly due to the decentralisation of services to most primary health centres within the country (Mutasa-Apollo, Shiraishi, Takarinda, Dzangare, Mugurungi, Murungu, Abdul-Quader and Woodfill 2014: 2). The HIV services in the Manicaland Province also improved in a quest to meet one
of the Millennium Development Goals, namely to combat HIV and AIDS within the country and to afford people longer life even though they are infected with HIV.

3.6 Selecting the research participants

Eight women aged between fifty and sixty-five years and living with HIV are selected to participate. They are recruited from the city of Mutare — one of the districts in the Manicaland Province in Zimbabwe. I decided on eight participants because qualitative research involves a smaller number of participants (Braun & Clarke 2013: 55; Silverman 2013: 201). Furthermore, issues involving HIV and AIDS are sensitive. There is a huge veil of secrecy which makes it difficult to identify and get participants to agree to participate in the project.

Only women are selected to participate in this study. I want a subjective and deeper understanding of a woman’s experience of living with HIV because women are mostly affected and infected by HIV in Zimbabwe (PEPFAR 2010: 2). As noted earlier, women are also stereotypically blamed for the spread of HIV and likely to be more stigmatised (Mawadza 2004: 420). In addition, feminist methodology theories suggest that it is easier to involve people who are more comfortable in disclosing sensitive information to those who share similar social characteristics (Braun & Clarke 2013: 88). As a woman, I feel interviewing women on issues surrounding HIV best enables them to open up and disclose ‘hidden and below the surface’ issues that qualitative researchers strive to ‘bring to the surface’.

Purposive sampling is the chosen method for selecting the study’s participants. Purposive sampling is used when deliberately selecting participants who are in a better position to provide relevant information to fulfil the goals of the research (Maxwell 2013: 97). It is used in order
to get rich data from information-rich participants who have the necessary knowledge and experience about the phenomenon under study (Patton 2002: 230; Flick 2009: 123; Suri 2011: 66). It can also be applied in situations where participants are difficult to recruit (Flick 2009: 122). As a result, there is a deliberate selection of participants who fit the criteria and fulfil the research objectives.

It is not the nature of qualitative studies to select a big and randomised sample such as in quantitative surveys where findings are quantified (Johnson & Rowlands 2012: 101). That is why I have a small number of research participants. Qualitative research mainly generates words and not numbers for analysis (Bricki & Green 2007: 2). Most knowledge produced and constructed through qualitative inquiry is contextual (Brinkmann & Kvale 2015: 64) and cannot be easily generalised to other contexts. The main goal of the research is to elicit subjective and intersubjective meanings of lived experiences, not exact answers (Braun & Clarke 2013: 19). In addition, qualitative research provides multiple answers (Braun & Clarke 2013: 19) and researchers seek depth instead of breadth in order to obtain a deep understanding (Thomas & Magilvy 2011: 151). Personal ‘truths’ relating to life as lived by the research participants rather than universal truths and generalisable findings are sought in qualitative studies (Webster & Mertova 2007: 89) because a phenomenon can be common but mostly experienced uniquely (Josselson 1995: 33). Thus, the findings of the research illuminate the individual meanings for a woman growing old with HIV.

Snowball sampling is used as a type of purposive sampling in order to get the required number of research participants. This study depends heavily on the involvement of information rich participants who are identified through key informants (Suri 2011: 69). The research participants are purposively selected through referrals from those who were initially identified
using criteria such as age (fifty to sixty-five years), as well as their willingness and ability to articulate their experiences about living with HIV. Braun and Clarke (2013: 57) confirm that snowball sampling involves recruitment through both the researcher’s and participants’ networks.

I recruited research participants through organisations that work with people who are living with HIV in the Manicaland Province in Zimbabwe. I approached the Zimbabwe AIDS Council District Office in Mutare which referred me to the Zimbabwe National Network of People living with HIV. I was then referred to different support groups working in the Manicaland Province including the Family AIDS Support Organisation and Windows of Hope. I got contact details of the strategically important people and coordinators for these groups. They were very supportive in making sure that I reach the required research participants.

3.7 Pilot study

A pilot study has an effect of validating data in qualitative research because it helps to ensure that the main purpose of the research is served (Hall 2008: 79). It also ensures that important issues are covered during the interview (Morse 2012: 197). Silverman (2013: 207) views pilot studies as an effective way to try, practice and improve interviewing styles and skills before starting with the real data collection. Hall (2008: 78) and Merriam (2009: 172) concur by in their view that pilot studies help to attune the data collection approach and to identify irrelevant questions, reformulate and reword confusing questions, and to include questions that might have been omitted in the initial interview schedule. The whole aim is to get good interviews since the questions we ask are instrumental in producing quality interviews (Chase 1995: 3). I piloted the interview schedule and the result of the pilot study was that I had to change some
of the questions on the original interview schedule and re-word some other questions. I also piloted the interview schedule with a woman who fits the criteria for participation in this study, that is a woman living in the Manicaland province who is aged between fifty and sixty-five years and living with HIV. Hall (2008: 79) points out that it is important to match the situation of a pilot study with that of the main interviews. On the whole, the pilot study was instrumental in contributing to the construction of meaningful interviews for my study.

3.8 Rapport between interviewer and interviewees

Interviews are regarded as social encounters (Holstein & Gubrium 2004: 141; Brinkmann & Kvale 2015: 22). As a result, it is essential that comfort and trust is established between the interview parties. Following Horn, Edwards and Terry’s (2011: 839) suggestions, I focus on the development of relationships to ensure that I gain the trust of the research participants. I managed to build trust through socialising with research participants before the interviews in order for them to feel comfortable in telling their life stories. I held informal conversations before the interviews as a way to open communication while establishing good rapport. Braun and Clarke (2013: 81) consider this as an important aspect in every interactive inquiry. I also earned the research participants’ trust by stating my clear and honest intentions and revealing the purpose of my study. The participants, as an indication of their trust, spoke freely and accorded me custodianship of their personal and intimate information. Some expressed their willingness to be photographed but I could not because it would have constituted an ethical breach of procedures stipulated in my ethics application form.

Trust can also be built through shared interests and concerns (Horn, et al. 2011: 839). I originate from the same part of the country as the participants and have a close female relative
who is ageing with HIV. This means that I share the same culture, values, understanding and practices of most of the participants. Hence, I did not appear too distant from the participants.

3.9 Data collection

Data in this project refers to raw information gathered from research participants that researchers use to get answers to their research questions and to achieve research objectives (Pawar 2004: 3). Data for this study is collected using semi-structured, in-depth and conversational interviews. Semi-structured interviews with open-ended questions suit a qualitative inquiry where the narration of experiences helps to communicate meaning (Chase 1995: 2). These interviews provide a platform for probing and thus allow flexibility for participants to express unanticipated ideas and bring additional issues into the interview (Braun & Clarke 2013: 24; Creswell 2013: 25&51).

According to Morse (2012:197), semi-structured interviews consist of a question stem (based on the issue to be covered) from which the interviewee responds freely. Depending on the response, the interviewer probes for depth or clarity (Brinkmann & Kvale 2015:10). This allows both parties to discuss issues that stem from the primary question. These stem questions in my interviews contain factual queries and are followed by probes on opinion and feelings. Most questions focus first on life as experienced and the follow-up ones on reflections and perceptions, as this is a phenomenological study which seeks to understand mainly the lifeworld. On the whole, I employ a funnel approach to questioning (Curty & Qin 2014: 2) — interview questions start with the general information gathering questions and go deeper into more personal and sensitive questions.
Brinkmann and Kvale (2015: 32-35) identify key phenomenological aspects that characterise semi-structured interviews in qualitative studies. These are, they are descriptive as they go further than general opinions of the lifeworld and meanings, and that they accord the interviewer deliberate naiveté where the interviewer is open to new and unexpected occurrences and themes of the lifeworld. Furthermore, they expose ambiguities in responses, are open to change on descriptions of themes and attitudes, accommodate varied levels of sensitivity on subject matters, afford interpersonal interaction between the interviewee and the interviewer, and can result in interviewees gaining new insights into their lived experiences (Brinkmann & Kvale 2015: 32-35). The interview questions for this study are open-ended which enable some flexibility in the way interview parties engage each other with a room to probe further and follow-up on issues of concern.

An interview, as defined by Wang and Yin (2012: 231), is a goal oriented conversation. To this end, interviews are guided by an interview schedule in order to meet the focused goals. In-depth interviews are used mainly to gather more private, personal information about people, their lived experiences, perspectives, emotions and values (Johnson & Rowlands 2012: 100). I apply a hermeneutical approach to gain a deeper understanding of growing old with HIV through the use of in-depth and conversational interviews. Hermeneutics involve an in-depth analysis of social situations (Myers 2013: 182) where an interviewer digs deep with the aim of extracting hidden information and knowledge (Johnson & Rowlands 2012: 100). In other instances, an in-depth analysis makes the things that are little known, clear (Neuman 2000: 70). This gives the researcher a better understanding of the state of things. During the interviews, I attempted to go beyond common sense and ordinary perceptions to obtain the contextual boundaries of people’s experiences (Johnson & Rowlands 2012: 102). In most cases, meaning is not something that is obvious (Neuman 2000: 71). As such, I use in-depth interviews to get
detailed information on the experiences of participants since qualitative research is interested in knowing and understanding people’s lives.

Interviews also involve the interviewee and the interviewer management of each other (Rapley 2001: 308). The interviewer must maintain a qualified naivety of one seeking to know the participants’ worlds through their points of view as they engage each other in the production of knowledge through interactional interviews (Gubrium & Holstein 2012: 32). Throughout the process, interviewees are supposed to be treated as the experts (Flick 2009: 178) and bearers of knowledge, whereas the interviewer has to learn and acquire knowledge through interviewees’ narratives (Johnson & Rowlands 2012: 102). In line with these interview notions, I bracket/keep my personal opinions at bay and allow interviewees to give accounts of their own experiences. I seek a deep level of understanding especially considering that I am carrying out the study as an outsider and not as part of their social setting. As such, all attempts are made to extract knowledge without being too intrusive. I encourage interviewees to express themselves freely and objectively so that the findings of the study lead readers to understand the interviewees’ experiences from their points of view. That means, to see what interviewees see, and to know what they know (Neuman 2000: 71). Therefore, the findings of the study are derived from the interviewee’s free expression of their experiences.

I end my interviews with a relaxed and easy question to enable the interviewees to shake off any anxiety that they may have accrued during the interview. As advocated by Braun and Clarke (2013: 81), interviews must have a good closing question that seeks to obtain other information that may have been excluded during the interview. The last question in my interviews acts as a tool to invite any information that the participant may want to add.
Clandinin and Connelly (2000: 110) recognise place and time as fundamentals that influence the quality of an interview. People often talk freely while in familiar places because of the intimacy and friendliness afforded by the place, especially when sensitive, emotional and private issues (like HIV) are discussed (Herzog 2012: 210). However, the interview location, as argued by Herzog (2012: 207) is not just for convenience or comfort as it contributes to an understanding of how people construct reality. Hence, there is often greater disclosure owing to familiar places, which compelled me to conduct the study’s interviews at places of the participants’ choice and in their home language.

All interviews are audio-recorded with the permission of the participants. The research participants had to sign for consent to be audio recorded (see appendix 4). Since qualitative research is concerned with detail, language and concepts that participants use in narrating their experiences, it is important that interviews are digitally recorded (Braun & Clarke 2013: 92). Researchers often do not write exactly what is said when taking notes, but may capture information to accommodate their personal biases (Johnson & Rowlands 2012: 106). The richness, credibility and trustworthiness of data can be compromised if only notes are taken because not everything that is said during the interview is captured, hence the use of audio recordings.

3.10 Data analysis

Data analysis is a process that involves making sense of the collected data by “consolidating, reducing and interpreting” what was said, read and seen (Merriam 2009: 176). Taylor and Bogdan (1998: 135) interpret data analysis as a process where the interviewer communicates to readers and tries to give readers a sense of “walking in the informants’ shoes” by making
them understand things from the viewpoints of the interviewees. Therefore, in this study, data is analysed to lead readers into understanding how life is for a woman who is living with HIV into old age. In preparation for data analysis, I transcribed audio-recorded interviews verbatim in the original language (Shona) and then translated them to English. Originality (a true version of the participant’s narration) is maintained in order to capture the true perspective of each individual. Hence, the research participants’ versions of their experiences are faithfully represented in the interview transcripts.

Preliminary and rudimental data analysis is done simultaneously with data collection to keep focused and avoid being overwhelmed with loads of data at one time (Merriam 2009: 171; Brinkmann & Kvale 2015: 216). Similarly, Taylor and Bogdan (1998: 141) maintain that data collection and analysis go hand in hand in qualitative research because researchers are always trying to make sense of the data they are collecting. I adopted this approach as I was collecting data and it assisted me to determine the point of saturation\(^5\), which I obtained with the sixth research participant. As such, the other two interviews were conducted to confirm the point of saturation.

Thematic data analysis is applied to identify key themes and patterns of meaning (Braun & Clarke 2013: 120). These meanings are derived from the spoken words and the hidden metaphors (Morse 2012: 197). Morse elaborates on the thematic analysis of data by stating that sometimes themes are “fore-grounded,” “back-grounded” or “present only by inference and revealed through indicators, signs, metaphors, or other means of interpretation” (Morse

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\(^5\) A point reached by researchers where no new information is necessary for further coding or formation of themes.
Hence, themes are derived from all features of the interviews. But focus is given mainly to the spoken words (content) than how they are spoken as suggested by Riessman (2005: 2) who considers content as the main focus in thematic analysis. Therefore, common themes are identified and integrated across interviews during the process of analysing data.

Thematic data analysis is done in phases although it follows a recursive process (Clarke & Braun 2006: 86). The identified phases include: familiarising with data, generating codes, searching for themes, reviewing and defining and naming of themes (Braun & Clarke 2006: 87). In articulating this process, I firstly read the interview transcripts intensively to familiarise myself with the data and at the same time to get inspiration for new interpretations of the phenomenon under study as pointed out by Brinkmann and Kvale (2015: 19). The process of familiarising myself with the data was not challenging because I personally conducted the interviews, transcribed and translated them. A critical consideration, delineation of short descriptions of each case and a systematic organisation of data resulted in the production of four major themes namely: pre-diagnosis experiences, post-diagnosis experiences, adapting and adjusting to the condition, and life in the future. Thereafter, I analyse the data deductively using theoretical lenses since data and theories are intertwined (Babbie 2014: 403). Data and theories inform and feed into each other (Braun & Clarke 2013: 43) to give the research focus.

Furthermore, I integrate reviewed literature into the data analysis process. Information from the literature enables me to take a critical stance as people can interpret reality in ambiguous and inconsistent ways just to suit their versions of reality (Shaw, Dyson & Peel 2008: 24). People, in expressing their experiences, often interpret them relative to their own purposes or to comply with social desirability. They seek value and justification for their actions in relation to their intentions (Baumeister & Newman 1994: 676). A topic-focused literature also gives
insights and propositions that help the researcher to interpret data (Taylor & Bogdan 1998: 146). In the process, not all participants’ views are taken at face value as viewpoints are compared with the actual reality to ensure a reliable ‘reading’ of the interviews. Therefore, incorporating theory and literature into data analysis leads to a more balanced interpretation. However, room is given for the unexpected, emerging concepts, interpretations and findings.

3.11 Credibility and trustworthiness

Credibility and trustworthiness are often given more attention in qualitative research than reliability and validity — which are more the pursuit of quantitative research (Webster & Mertova 2007: 5). Throughout this study, rigour is sought in order to get quality, credible and trustworthy data, as advocated by Tracy (2010: 841). Extensive data collection is done through in-depth interviews as one way to demonstrate rigour (Creswell 2013: 54). In addition, the multiple levels of data abstraction that I employ add to the rigour (Creswell 2013: 54). Besides, basic principles of hermeneutics, which also inform my data gathering, analysis and interpretation, allow for the end result to be believable and trustworthy. Hence, the study comprises of information that is thoroughly gathered and analysed in order to uphold credibility and trustworthiness.

Credibility and trustworthiness are also attained by limiting personal negative bias. In this respect I attempt to keep my personal views, emotions and other preferences at check during the interviews in order to reflect a true version of the interviewee’s story as advocated by Johnson and Rowlands (2012: 101). I achieve this by guiding and not controlling or shaping information from respondents during the interviews. Gubrium and Holstein (2012: 33) warn interviewers against controlling participants’ opinions or leading them towards the
interviewer’s personal preferences. Interviewees are encouraged to tell their stories freely so that data is gathered in a co-operative and uncontrolled way. By so doing, the interviewees own their stories because they are given a ‘platform’ to voice their experiences. Furthermore, the way I transcribe the data, namely verbatim, is also regarded as a method that enhances trustworthiness of data (Braun & Clarke 2013: 162-163). Spoken words, in this study, are transcribed as said and include direct quotes from interviewees in the findings. Boyce and Neale (2006: 9) view the inclusion of direct quotes as a way to contribute to the credibility of the information presented.

Furthermore, being knowledgeable of a process produces pragmatic data which counts as a tool for credibility (Kvale 2007: 142). A researcher needs ‘intellectual craftsmanship’ to produce quality knowledge (Brinkmann & Kvale 2015: 73). I did everything in my power to gain this ‘intellectual craftsmanship’. I participated in the Narrative Study of Lives (UFS) programme workshops on interviews and data analysis as well as the University’s Postgraduate School workshops on qualitative methodology where I successfully completed an assessment and received a certificate of competence in qualitative methodology. I was also mentally prepared to go into the research field as a result of the psychological support that I sought before data collection. Hence, this study is conducted with the ‘intellectual craftsmanship’ necessary for it to be deemed credible and trustworthy.

Ethical considerations for this study, discussed in the next sub-section, also contribute to the trustworthiness of my research findings. According to Rossman and Rallis (2011: 68), a study conducted ethically is a trustworthy study.
3.12 Ethical considerations

Ethical considerations are regarded highly at all levels of this study in order to acquire knowledge in a responsible manner. Brinkmann and Kvale (2015: 85) encourage researchers to consider ethical issues at all the stages of the study. Tracy (2010: 837) identifies ethics and its considerations as a marker of quality in qualitative research. Certain stipulations on ethical requirements which are identified by Braun and Clarke (2013: 63) and discussed in this section include seeking permission, obtaining informed consent without any deception, maintaining confidentiality and anonymity, ensuring participants’ right to withdraw from the study without any negative repercussions, ensuring no harm is done, and being honest in reporting findings.

3.12.1 Permission to conduct research

Creswell (2013: 55) advocates for researchers to be very considerate and sensitive to all ethical issues including collaborating with relevant stakeholders for entry into the research site. In addition, Braun and Clarke (2013: 61) advocate for researchers to engage, not only with the research participants, but also with the academic and the wider-world community. As such, no data collection commenced before I was cleared by the University of the Free State’s Humanities Faculty Ethics Committee (see appendix 1). I also got permission to conduct the research from the Zimbabwe Medical Research Council (see appendix 2).

3.12.2 Informed consent

Prior to the actual interviews, participants were informed of the purpose of the study and all the dynamics of the interview so that they could make an informed consent to participate in the
study. Therefore, all participants got involved out of their own will, after receiving an explanation of the purpose of the project, and having agreed to the contents of the informed consent form that we discussed in their home language. I follow the stipulated ethical considerations in which I ensure that consent is given by a person who is competent to do so, is satisfactorily informed and also that consent is given voluntarily (Flick 2009: 41). As such, all participants were in a position to give their own consent to participate in the study.

3.12.3 Mitigation of risks

Being ethical is more than just seeking permission to conduct research. It also involves being aware of and addressing all the moral issues involving the research (Creswell 2013: 54). Researchers need to be on the look-out for any risks that might arise from their research in line with the principle of “doing no harm” (Braun & Clarke 2013: 63). They must guard against carelessness, insensitivity and any illegal activities during the course of their research. As such, I was and still is always on the look-out for anything, including unintentional disturbances to research participants. I have prior training in HIV6 and I am aware of the sensitivity of issues involving HIV, particularly as the research participants are older adults. This sensitivity played a role in the way I formulated the interview questions and in carrying out the actual interviews.

I also agree with Brinkmann and Kvale’s (2015: 83) position that interviewing has the potential to pose harm to anybody. Principles of sound ethics stipulate that researchers must take steps to avoid harming participants (Flick 2009: 37). I understand that this research has a high

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6 I hold an MPhil in HIV/AIDS Management and have worked with HIV-positive people at various organisations.
potential of evoking discomfort, so research participants were informed that they could withdraw participation at any time should they desire to do so and that they must answer only questions that they are comfortable to answer. I also warned them beforehand of questions that might affect them emotionally. Therefore, although no form of harm was anticipated, all efforts were made to protect the wellbeing of the research participants. I arranged for counsellors from St Werburgh's Clinic through the Portland Mutare Sister City Association\(^7\) (PMSCA) Country Coordinator, to be on standby for any need for emotional support for participants.

### 3.12.4 Confidentiality

Research ethics also consider confidentiality as a requirement to protecting human subjects (Bell 2014: 51). I prioritise confidentiality highly throughout the course of the study. Data is de-identified and stripped of all identifiers of personal information. No information that directly links the research participants to the data or to anywhere within the dissertation is provided. I use pseudonyms or fictitious names for all research participants, the people they mention during the interviews, and places that directly connect them to the information supplied in an effort to protect anonymity. In addition, all digital recordings, notes and transcripts are protected so that they are inaccessible to other people. Overall, my research participants are protected and anonymity and confidentiality will always be maintained even in subsequent publications.

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\(^7\) St Werburgh’s Clinic is one of the PMSCA projects.
3.12.5 Appreciation of participants

Researchers are encouraged to find ways of giving back to participants where possible (Creswell 2013: 55). They can do so in small tokens, such as vouchers (Braun & Clarke 2013: 61). *The Narrative Study of Lives* programme at the University of the Free State has an ethical consideration that allows the thanking of participants for their time, effort and role in research. As such, they facilitate thank-you tokens in the form of vouchers for research participants. As one of the students in *The Narrative Study of Lives* programme, I used grocery vouchers to show appreciation to my research participants.

3.12.6 Exiting the research field

Upon leaving the research site, I bade farewell to the participants and to all those who made data collection possible. Creswell (2013: 55) warns researchers against leaving participants with a feeling that they are abandoned. Researchers must communicate information about their departure to participants (Creswell 2013: 55). I saw it as appropriate to inform the research participants that I was leaving the country (Zimbabwe) and they all expressed their willingness to have contact with me should the need arise. In summary, ethics in research protect the interests of all research parties because it deals with moral issues. This project is conducted as responsibly as possible because it deals with human subjects who are also vulnerable because they are HIV-positive and ageing.

To conclude, this chapter gives an account of the study’s methodological issues. It outlines the nature of this research, its aims and objectives, how participants were recruited, and how data were collected and analysed. It also covers issues related to ethics and other practical matters.
The gathered data is from HIV-positive women who are purposively selected. The women give their account of experiences through audio-recorded in-depth and semi-structured interviews that I analyse thematically. A true reflection of the participants’ experiences is maintained and all efforts are made to produce a credible study.
CHAPTER 4 — DATA ANALYSIS

This chapter presents the findings from the data collected through semi-structured interviews with eight women who are growing old with HIV in Manicaland, Zimbabwe. It also contains discussions that synthesise the findings with the relevant theoretical aspects and reviewed literature. Most interpretative studies adopt this approach whereby the findings, analysis and discussion are not presented separately. This, according to Thomas (2009: 227) allows the researcher to test emerging findings against his or her own opinions and to integrate the findings with the available literature. Therefore, any validation or confirmation, or juxtaposition of findings against the reviewed literature is presented simultaneously.

Themes are developed according to the experiences of this group of older women who are living with HIV. I use codes to order the data contained in the interview transcriptions. In this way, I identified more than two hundred and fifty different issues mentioned by the research participants during the interviews. These two hundred and fifty different issues are grouped together into larger categories and four overarching themes. The four themes, which are briefly described in the figure below, are: pre-diagnosis experiences, post-diagnosis experiences, adapting and adjusting to the condition and life in the future.
<table>
<thead>
<tr>
<th>PRE-DIAGNOSIS EXPERIENCES</th>
<th>POST-DIAGNOSIS EXPERIENCES</th>
<th>ADAPTING AND ADJUSTING TO THE CONDITION</th>
<th>LIFE IN THE FUTURE</th>
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<td>- Understanding the condition</td>
<td>- Hopes</td>
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<td>- Fatalism</td>
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<td>- Denial</td>
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**Figure 3: Key themes**

The theoretical context and literature on the topic of living with HIV (cf. chapter one and two) provide a background against which to analyse the research participants’ narratives. This is a phenomenological study that focuses on experiences of the lifeworld (Sokolowski 2000: 87) and therefore the identified themes derive from research participants’ immediate experiences of their social reality. Thus, their experiences are analysed within the context of their lifeworld. Nonetheless, a synthesis of theoretical constructs, available literature on previous research and the analysis of the data, provide a nuanced understanding of everyday life as experienced by the female research participants who are in the process of growing old with HIV.

Furthermore, the themes are developed while keeping in mind that experiences are located within a historical time framework (Inglis & Thorpe 2012: 101), temporal and occur simultaneously (Rogers 1983: 37) — section 1.2.2, pg.20. The four major themes are therefore
organised in temporal order with reference to life before HIV infection, life after the HIV diagnosis, life during the period of adaptation and adjustment to the condition, and life in the future.

The average age of research participants at the time of the interviews is fifty-four years with a range of between fifty to sixty-one years. All research participants acknowledge that they are living with HIV and reveal that they are on antiretroviral therapy and belong to an HIV-focused support group. Everyone, except for one woman, is widowed and the death of their spouses was caused by AIDS-related conditions. Among them, none has or had a professional career. Five of the participants were once cross-border traders who traded their merchandise between Zimbabwe, South Africa and Mozambique. At the time of conducting this study, no one is still involved in that business with the participants citing, as reasons for no longer practicing this business, their age and problems with their legs.

4.1 Pre-diagnosis experiences

In an attempt to provide an introduction to understanding the nature of the research participants’ total life experience, I start the data analysis with an exploration of the participants’ lived experiences before they knew, or before confirmation that they were living with HIV. As highlighted in the chapter on the theoretical context, lived experiences are explained as the everyday life encountered by people as they live, sustain, renew, recreate and transform it (see section 1.2.2, pg.20). Therefore, I follow this notion as I explore the research participants’ lived experiences.
An analysis of the research participants’ narratives reveals that a pre-diagnosis phase is a period of inactivity and unawareness of what exactly would be happening in their lives as they could not imagine what it may be like to live with HIV. They lived in suspense, denial and sometimes with fatalism regarding HIV. Except for one woman who was diagnosed with HIV only five years ago, the other seven participants’ HIV statuses were confirmed a long time ago, with the longest being twenty one years. This means that most of these women got infected with HIV in their late twenties and early thirties. For this reason, I explore their experiences back in those days when they were younger. I also include, in this section, the way social forces impact on their experiences, especially, on their perceptions of HIV risk both as older women and at the point of infection when they were younger.

As younger married women with young families, most of them realised it now, many years later that HIV has been at the center of most of the disruptions that they were facing in life. Nearly everyone had an unpleasant experience of HIV as evidenced by the illness and loss that research participants were subjected to. Hence, HIV took a prominent and traumatic role in the participants’ lifeworlds — a role Holzner (1972: 13) calls a reality shock. The participants’ normalcy of their lifeworld had been confronted by threats and uncertainties that affected their social order (Holzner 1972: 13) as HIV interfered with their everyday lives. These threats and uncertainties led them to both take HIV tests and seek factual information about HIV, which in turn played a role in restoring normalcy to their lives years later.

It appears from the interviews that at some point, the research participants’ health encounters triggered some suspicions of an HIV infection. They became suspicious because they had suffered HIV symptoms or observed such symptoms in their family members before they died.
from AIDS-related illnesses. Grandma Mecky’s narrative to describe both of these aspects, is
telling:

... the way he was sick and then his death certificate ... [I suspected] there
is something [related to HIV]. [I thought] it might be something related to
this modern disease (HIV). ... I had sores that I developed on my [private]
parts and it was very painful. I was sick. When I was sick like that, I could
not sit like this (upright). I would lie down most of the time. That is when
I said: “Since I was born, I have never got sick like this. I have never seen
a sickness like this”. (Grandma Mecky)

Grandma Kate’s situation is different in that she suspected an HIV infection but did not want
it confirmed. Denial is often a common state that people with HIV experience as they struggle
to acknowledge the presence of HIV in their lives, as Duracinsky, Herrmann, Berzins,
Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter and Chassany (2012: 5018) note. HIV,
as a stigmatised condition in Zimbabwe (Campbell, Skovdal, Mupambireyi & Gregson 2010:
978), can relegate a person to a minority social status within a society (Katz 2014: 1). As a
result, some people try to disassociate themselves from it. Such people do not want to be
viewed as misfits in their societies because of a socially undesirable condition. As it turns out
from the interviews, people’s negative portrayal of HIV made it difficult for some research
participants to acknowledge HIV with ease. In addition, the extent to which the life-threatening
state of HIV was portrayed within society instilled fear and despair in many people. This is
how Grandma Kate reacted when it was suggested that she get tested for HIV:

When I knew [that I have HIV], I started by having boils. Boils, and the
doctors would take them off and one of the doctors suggested that I get tested
for HIV. Eee, I ran away (laughs). ... Eee, aah, that you have AIDS... I think
the way people talked about it made people to be afraid of it because people
would say that you were going to die. So there is no one who wants to die,
plus there were no ARVs yet. So you would know that if they say you are HIV-
positive you were going to die. (Grandma Kate)

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8 Unless stated otherwise, the cited sources are discussed in the literature review chapter
Others had their reality shock experience through the loss of family members. Grandma Jessy, a 50 year old widow who knew the symptoms of HIV at that time and had experience of witnessing her family dying of HIV-related sicknesses, expresses her suspicion of having contracted HIV in the following way:

*I cried but I knew personally that it was not possible for me to be diagnosed the other way, because my family had perished because of HIV.* (Grandma Jessy)

The pre-diagnosis phase is mainly associated with lack of knowledge of the problem; this was the case for all of the research participants, who lived with the virus for a long time without realising it. Some suffered from HIV symptoms but did not know that it is HIV while some would only have those symptoms treated without any HIV test. HIV is known for being latent for some time before it manifests in symptoms such as opportunistic infections. In the case of Grandma Tamar, her HIV-positive status was confirmed only after losing two babies. She and Grandma Mecky describe their experiences as follows:

*At first I did not know what it was. Aah! I was living just as a person and knew through death, that: Aah! This is what I am now (HIV-positive). … Yes, my baby passed away and then on top of that I had a still birth … without knowing that it’s HIV …* (Grandma Tamar)

*I went to the clinic and got treated without even getting tested. Up to a time when I developed herpes, that is when I was told that your immune system is weak.* (Grandma Mecky)

It is clear from the interviewees that some research participants were fatalistic about HIV. They did not bother about HIV before getting tested for it and admit that HIV took them by surprise. They realised its ramifications when it was too late to avoid infection and/or its effects. A consideration of these discussions in relation to their life as married women shows that their perception of HIV as a direct risk was low. Research points out that evading HIV
infection when married can be very difficult (Mbona 2012: 9) because married people are less likely to practice protected sexual acts. Grandma Mecky’s confession in the following quote where she talks about how she never imagined any problems because she was married, supports earlier findings that suggest that married women are often oblivious of the danger of HIV infection in their matrimonial relationships (Higgins, Hoffman & Dworkin 2010: 436).

In many ways, trust becomes a social barrier to HIV prevention among married people. This point is evident in the following excerpts that show the research participants’ failure to see the necessity of testing for HIV:

*When HIV came to us, it came when we were not aware of it. S-o-o they say that the first cases were reported in 1986, [19]82 somewhere there. So we were not even knowledgeable about it to the extent that we said: “Now that we are married, what else do we want?” We never thought about anything and even when we started to get sick we never suspected anything (HIV infection).* (Grandma Mecky)

*So, at some point in 2011 when I got back from South Africa. When I got here (Zimbabwe), he then told me that this is what I am. But he did not tell me that he is (HIV) positive. He just said: “Let us go and get tested”. Then I said: “Aah! To get tested for what?” ... He said: “To get tested only”. ... I said: “Aah! I cannot go there to get tested because there is nothing that I do that makes me think that I can get tested for HIV”.* (Grandma Maybe)

Further analysis of the data on the pre-diagnosis phase shows that people can fail to believe that HIV is behind some of the problems they face. The research participants believed then that there was a spiritually connected root cause behind their misfortunes. Such assumptions are consistent with previous studies (Bogart, Skinner, Weinhardt, Glasman, Sitzler, Toefy & Kalichman 2011: 181; Tenkorang, Gyimah, Maticka-Tyndale & Adjei 2011: 1001; Mbona 2012: 5) that report on the way sickness is commonly associated with witchcraft. This belief is often cast aside, with time, as research participants take the decision to medicate themselves and acknowledge the existence of HIV in their lives. The way they narrate this shift displays
no humiliation in what they once believed in — something I attribute mostly to wisdom that develops over time and with age. Here is an example to demonstrate this:

... because myself before I got treated (ART) I also thought that I was bewitched. Even when my husband passed away, I also thought that he was bewitched. Yes, but now I know that it is HIV. (Grandma Jessy)

In other cases, some participants could not acknowledge HIV because of the confusing way it manifests in a person’s body. Here is how some recount their experiences:

But I later lost a lot of weight — my body getting smaller and smaller, bit by bit. And I once thought that it is stress, because I had lost my husband plus I was not employed what-what. So I thought maybe it’s just troubling thoughts that are too much for me. (Grandma Mecky)

Myself I did not get tested at that time because I was very strong. Aah, I was left (husband died in 1997) and stayed for long and I was telling myself that I am strong and healthy. I later started to get sick in 2005. That is when I started to get sick and other people would say: “Your husband did not die of AIDS”. Because I was strong, I refused to get tested. I said: “Haa I don’t have it (HIV) because I am strong”. And I had nowhere that showed that I was not well, even showing that I have the disease (HIV), nothing. (Grandma Kate)

Even some of the research participants’ relatives initially failed to accept that the deaths were AIDS-related. They based their views about the cause of death with the physical appearance of the widow and concluded that if the widow looks healthy, their relative could not have died of AIDS. AIDS widows are consequently blamed for their husbands’ death. This quote is telling:

It was difficult because people did not understand. In fact when my husband died even his relatives did not accept it that he had died of AIDS. They thought that I am the one who killed him, like: “Haa no, this is the one who killed him”, this and that. (Grandma Kate)
While others lacked transparency on the exact problem, others were powerless to confront the risks that threatened them. Some of the women were at some point aware of the HIV risk but could not take any action. According to them, their health was put in danger by their husbands’ infidelities but they felt powerless and helpless. Findings from a broader discussion on the life of a married woman reveal that some married women experience restrictions in the way they express their feelings to their husbands. This is consistent with Mugweni, Omar and Pearson’s (2015: 388) finding that most women in heterosexual relationships lack the assertiveness to question their man’s sexual behaviour. Also theory suggest that the cultural meanings related to sexuality are significant in regulating sexual experiences (see section 1.3, pg.24). Thus, the women’s freedom of expression is weakened by society’s rigidly defined and expected role behaviours of women, as pointed out by Lindsey (1997: 2) (see section 1.5.1, pg.35). Women can also be ill-equipped to dispute actions that pose the risk of HIV infection, thereby drawing empathy from those who view them as innocent victims. The following quote confirms this observation:

*You will know that a woman has nothing that she can do or say. Even if you know that your husband is looking for other friends (sexual partners) or sleeping at that shebeen or that your husband slept at a girlfriend’s place, where you even know, there was nothing you could do. But you will know that when he comes, you will know that he is my husband. You will just meet (have sex) like that. We did not have an opportunity to say: “No-no-no, let us use a condom”. (Grandma Mecky)*

However, now as older women, they view this in a very different way, perceiving a culture that supresses the voice of many women as problematic and expressing their willingness to challenge it. They even advocate for people to consider HIV as they perform cultural activities. Grandma Mecky describes how culture limits married women and how this generally impacts on their assertiveness in sexual encounters:
Also our culture says that we must not wear gloves but we are teaching people that because of HIV, these days there is HIV. Put on the gloves when you are bathing a sick person or even a dead one. We are telling them that we are not saying do not bath them, but use gloves to protect yourselves but our culture will be seeing it as if you are ... That is, detesting your sick or dead relative. (Grandma Mecky)

Others failed, back then, to raise the issue of risks of HIV infection with their husbands because of the fear of blame. In aligning themselves with the social norm of not being a ‘trouble-maker’, some of the research participants felt it would be better not to raise the issue of condoms to prevent HIV, than to be blamed for it. The following quote from Grandma Kate describes some of the challenges that women face in heterosexual relationships. It also highlights how women sometimes sacrifice their health for having a socially acceptable persona:

>You will be blamed and he will say: “You are the one who started it”. And yet you are doing nothing, you are very faithful. Then he will say: “This prevention thing, where did you get it from?” So you just keep quiet and keep it inside. (Grandma Kate)

Her non-use of preventive methods in the face of a health risk is typical in many African women and corroborates Mugweni, Omar and Pearson’s (2015: 390) finding that most married women cannot refuse sex with their husbands. Some of the research participants were caught between two difficult situations which are considered as socially intolerable for a married woman — either to refuse sex or to demand protected sex.

Grandma Kate’s story is a major insight as she also touches on age in her description of how difficult it is for women to be assertive about protected sex and HIV prevention issues. Her tone indicates a sense of desperation on the part of women who are older. They are at an age where they cannot separate from their husbands even if the husbands cheat on them. They also
cannot leave their husband’s family because they are old and under pressure to retain that social status of being a loyal woman. Here is how she describes it:

*Even when you see that this man is unfaithful, you just stay with him. Where can you go because sometimes you have passed your reproductive phase. You have grandchildren now, so where can you go? And sometimes no one between your parents is still living. They are all dead. So we get troubled a lot, us women.* (Grandma Kate)

Another finding relates to the socio-economic situation of women and its influence on their lived experiences. It is clear from the interviews that some research participants were helpless in the face of their loved ones who were dying from HIV because of a lack of financial resources to meet the medical costs. It is evident that women’s socio-economic status not only makes them vulnerable to HIV by being dependent on their husbands, but also takes away their power to meet their loved ones’ medical needs, especially when an income earner (husband) is incapacitated. As a stay home mother, Grandma Jessy recounts how she felt helpless in her efforts to save the lives of her children because HIV medication at that time was not yet freely available to people in Zimbabwe:

*I was aware myself [that it is HIV]. I knew already but there was nothing I could do because there were no pills (ARVs) [available freely] by then. That is when it was said that the pills (ARVs) are being sold and they were very, very expensive what-what.* (Grandma Jessy)

The discussion with Grandma Tamar on powerlessness in the face of risk, also highlights some of the life challenges that women face with regard to the management of HIV. She mentions that women’s inaction is sometimes a result of men’s failure to consider women’s voices. This illustrates the lack of balance in most heterosexual relationships in patriarchal societies as reported in Muller (2005: 31). This is Grandma Tamar’s view in response to the question on how easy it is for a woman to tell her partner that she has been diagnosed with HIV:
It depends on how the partner ... how you talk to each other [and] where you end up at. Since you are together, you study each other. That this man, is there anything that he listens to, anything that the wife says. Or that, is there anything, any words that when a wife talks he will say: “O-o-h, these words are wise, these words are good”. Because men do not listen to their wives. So there are some women who cannot get the chance to talk about such things, that this is what is here. They think ... what I say is rubbish, it does not work ... (Grandma Tamar)

In addition to being powerless in the face of health risks, there are instances where some participants could not combat HIV because of non-disclosure of HIV by those who were aware of it. In the identified cases, health practitioners did not diagnose HIV openly or the research participants’ spouses (who had taken an HIV test without their knowledge) did not reveal that they were living with HIV. This confirms the argument by scholars such as Nhamo, Campbell and Gregson (2010: 1662) that some societies have limitations and unwillingness with regard to discussions on issues involving sexuality and HIV. As a result, the research participants were deprived of a free platform to discuss HIV issues with their spouses and health practitioners. Such instances are evident in the following accounts:

*And in that year — 1994 when he died, they (doctors) said it was TB-related. They did not exactly tell us that it was HIV. ... All the doctors we visited, even the post mortem indicated that it is TB-related.* (Grandma Mecky)

*For him it was his second time. He had done an HIV test before, alone without me, but he did not tell me. He did not say a word about it.* (Grandma Maybe)

In summary, the themes discussed in this section focus on women’s experiences before it was confirmed that they are living with HIV. Some of them had their suspicions about HIV but in most cases, HIV was confirmed at a very late stage after experiencing disheartening disruptions in their lives. There are also cases where, as women in gendered, patriarchal and unbalanced heterosexual relationships, the research participants were either unable to avoid
HIV infection or could not afford to save their family members as they die from AIDS-related complications.

4.2 Post diagnosis experiences

The second major theme in the data analysis deals with the research participants’ experiences after they had been diagnosed with HIV. This section covers the analysis of the participants’ lived experiences by focusing on existential issues including their reactions, behaviours and mind states after being diagnosed with HIV. It also presents the feelings relating to the participants’ disclosure of their HIV statuses to people of their choice. Existential phenomenology, one of the theories on which this study is based, provides a framework for the analysis of research participants’ experiences and feelings as they face changes in their lifeworlds. I employ existential phenomenology to explore the psychological affects (feelings and emotions) that HIV and age bring to the experiences of the research participants because, as stated in the theory chapter, existential issues are both philosophical and emotional (Kotarba 2012: 141).

The research participants experienced discomfort after realising that they are living with HIV. Some felt uncomfortable about telling others that they have such a condition. The findings also reveal that some of the participants could at first not find any purpose of living and as such harboured several negative thoughts. This is mainly due to the fact that HIV still remains an undesirable condition and that they felt they could not live with such a despised condition. The research participants state that the revelation of an HIV infection made them feel hurt. Emotional hurt is one of the forms of psychological distress that accompany an HIV-positive diagnosis, as stated in Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf,
Fournier, Schechter and Chassany (2012: 501). In explaining their reactions and feelings, the research participants indicate that they got distressed by an HIV-positive diagnosis because they were never unfaithful in their marriages. One of the research participants narrates her experiences in this way:

_Eee, I was hurt. I felt hurt because I never imagined that situation to happen to me. Because I was married to my husband when I was a virgin, and I was very honest. That is the truth. There was nothing that I did. Yes, so it was hurtful to me that today I am now told that I have HIV. But I did not go around looking for other friends (sexual partners). It felt very hurtful._ (Grandma Kate)

Some of them admit that various disturbing thoughts crossed their minds upon realising the truth about their HIV-positive status. Two of them admit to contemplating suicide as they felt, at that point, there was no basis to continue living with a condition that society despises. They were confronted with a reality shock (Holzner 1972: 13) and could not immediately think of any ways to reconstruct reality towards living a meaningful life. This finding is consistent with studies, such as Capron, Gonzalez, Parent, Zvolensky and Schmidt’s (2012: 301) which report links between HIV and suicide. With such threats to the existential being of a person, suicide seems like an option to many people after an HIV diagnosis as Grandma Maybe expresses:

_At the same time I was thinking that it is better to die than to live a life of a sick person. Because it was being said everywhere that this disease (HIV) cannot be cured, once you get it you have it for life. So I thought of suicide and I started to think of my friends; what they were going to say if they hear that I am sick._ (Grandma Maybe)

It is also common for people to contemplate the purpose and meaning of life when facing a life threatening condition like HIV, as Milam (2004: 2354) reports. The common and intersubjectively-constructed assumption is that HIV equals demise and that the beginning of HIV is the end to everything. This is partly because society generally considers an HIV
infection as a life-threatening condition (Sawyer, Ayers & Field 2010: 437) that inevitably translates into death for those who are living with it (Mayers, Naples & Nilsen 2005: 94). The research participants’ stories reveal how emotionally disturbed they were upon realising that they have contracted a condition that is heavily despised in the society. Apparently, everyone was calling AIDS ‘Shuramatongo’ — loosely translated as a “disease of destruction” because couples were dying successively within a short span, hence the participants’ distress.

One element that the theory chapter explores (cf. section 1.2.3, pg.22), is that there are common assumptions in the lifeworld, which lead people to hold a collective understanding of a phenomenon (Sokolowski 2000: 152). I note, in my analysis of the findings that, some of the research participants initially thought that there is no life after HIV, since this is the collective and general assumption in society. The most common statements demonstrating this collective supposition are:

_I can say the first days when I got sick. So I can say those days are the ones where people said many things about AIDS because the number of people who were getting ill was becoming big, and people were getting very-very sick and eee... Others were dying because there was no treatment that time. People then said: “AIDS, ahh, is Shuramatongo”. But these days things are better now because people now know a lot of things about this disease. Plus it’s now everywhere, everywhere. You find it everywhere, so people now know._ (Grandma Kate)

_Eer, those days it was frightening to hear that you have AIDS. People would say: “You have AIDS! Yaa, you are going to die!” And for sure many people died because they did not know. They did not get help. So I was worried that being sick like that, I was going to die and leave my child without a mother and father._ (Grandma Rose)

However, others defied those collective assumptions and applied life-saving steps:

_This one (child) doesn’t have anything (HIV) because I was now aware. I knew that time that I have HIV. I then got taught that if you need to have children, you can still have a child who can survive. ‘Don’t be afraid that you will have a child who does not live because you are now positive living_
(HIV-positive), don’t be afraid”. Because during that time eer, for sure people said you cannot have a baby who lives but I did not get scared. (Grandma Tamar)

Grandma Mecky is one such person whose thoughts were intersubjectively influenced by negative collective beliefs when she tested positive for HIV. She points out that she thought that her death was imminent. Her life looked so gloomy during that time of realisation after her HIV-positive diagnosis that she began to make arrangements for her death:

I was hurt and I said: “How am I going to support these children that were left to me”. I was hurt and I cried. I called my brother who stays in (Name of town withheld for anonymity purposes) and I said: “My brother come here, you must keep my children well. I am asking you to take care of my children”. I thought I was also going to die since HIV was killing many people. ... I called him and said: “My brother I am dying”. I even wrote a will that if I die my brother is going to take care of my children. (Grandma Mecky)

In a context of HIV as a psychological stressor as reported in Nightingale, Sher and Hansen (2010: 452) and Sawyer, Ayers and Field (2010: 436), some of the research participants admit that they were severely shocked by the fact that they are HIV-positive. An HIV diagnosis shocked them, except for two participants who confess that they received the news with calm.

The struggle to find meaning in life whilst living with the news of having acquired a serious medical condition led the participants to contemplate the existential ‘why?’ questions. Their tone communicates a feeling that HIV is for wrong-doers and they do not deserve it because they did nothing wrong. Grandma Maybe asked her husband if HIV was a ‘thank you’ for all the hard work she put in towards the upkeep of the family. Beneath her narrative, and those of some of the other research participants, lies some undertones of blame whereby a wife feels that her husband is the bringer of this undesirable condition to the family. This contradicts
people’s perceptions that women are perpetrators and vectors of HIV (Mawadza’s 2004: 429) and refutes too the view that men are victims of HIV (East, Jackson, O’Brien, & Peters 2012: 16). Instead, it reveals the extent to which women can be victims who unwillingly contract HIV through their sexual partners as reported in McDonald (2012: 14) and de Souza (2010: 250). The next quote is expressive:

_Haa, I got troubled. I was affected, I do not want to lie. It troubled me. I took almost 3 months going for counselling. Each time I looked at him, I would feel all my anger coming. I then asked him, “What is this now?” “Is this the thank you I get for supporting the family?”_ (Grandma Maybe)

A further probing for those who expressed calm and less stress upon HIV diagnosis produced these excerpts:

_**I don’t want to lie that I felt anything bad. I just took it as if I had flu.**_ (Grandma Tamar)

_**I don’t want to lie, there was nothing that came to my mind. Aah, I accepted it. I did not get worried. I was even happy that this came out because I now know what was eating my body.**_ (Grandma Shelly)

I asked them to point out how they managed to acknowledge an HIV diagnosis with no distress. They said that their reaction during that time was motivated by the fact that they were not the only ones in that condition. Phenomenologically, it indicates the intersubjective nature and the shared reality of everyday life. People’s interactions and perceptions are often shaped by other people’s experiences (Sokolowski 2000: 152). The following quotes reflect that level of intersubjectivity in a society:

_YES, I just accepted it. I think: Eer, it’s because of people – many people that I had seen. Those with HIV. I knew that this disease is now common and other people are having it._ (Grandma Tamar)

_No, I didn’t [get worried]. In my mind, I was thinking that it might be this disease (HIV) ... And I also saw it with my own eyes that a person with_
this disease loses a lot of weight and becomes very, very thin to unbelievable levels. (Grandma Shelly)

What is also striking is Grandma Maybe’s complete change or ‘U-turn’ in her narrative – the one who was angry and asked her husband if HIV is a ‘thank you’ for supporting the family. Throughout the greater part of the interview, she expresses her disappointment with the fact that she is infected with HIV yet she is a faithful wife. Then at one point, she blames herself for leaving her husband for a long time while on business in South Africa. Here, she is clearly trying to align her views with that of most people in the society who believe that women should stay home as carers (Poku 2005: 99) and men go away from home working (Bassett & Mhloyi 1991: 143). This is what she says with regard to her condition during the initial stages and when she makes a complete change of view:

But as time goes on, I got to a point where I told myself that it happens [to be HIV-positive]. And when you later look at it, you will see that a man must not stay alone for long. (Grandma Maybe)

Further analysis of the research participants’ experiences during the post-diagnosis phase shows that the study participants feel obliged to tell other people that they are living with HIV. In most situations they told people who are close to them first — probably because they thought that close people are less likely to stigmatise them. Literature shows that people often fail to disclose an HIV-positive status for fear of negative reactions (see section 2.7, pg.61). Grandma Tamar first told her husband, while Grandmas Vicky, Mecky and Maybe first told their children, with Grandmas Kate, Jessy and Rose first telling their sisters, and Grandma Shelly telling her friend first.
Some disclosed their HIV status at a point where they were feeling very sick. For example, Grandma Rose took an HIV test and kept her HIV-positive result a secret, later on became sick and took another test and disclosed her status that her health is compromised by an HIV infection after realising that her condition could not be hidden anymore. This is consistent with Gilbert and Walker’s (2010: 143) report that sometimes the symptoms of an infection can be so overwhelming that they force an involuntary disclosure. Her narrative goes like this:

She (sister) was the first person to know when I got tested because I was very sick. Yes, but when I first went for testing at New Start [HIV counselling and testing centre] it was my own secret. When I got sick, that is when I had to do a test again. That is when she was the first person to know that her sister is now what, is now [HIV] positive. (Grandma Rose)

Other people are driven by tradition to disclose their HIV status to relatives. As discussed in chapter two (see section 2.7, pg.61), some social norms relating to sickness dictate that a person is obliged to inform relatives about any serious health condition that would have afflicted them. Based on this custom and on the view that disclosure can be culturally determined (Donahue, Dube, Dow, Umar & Van Rie 2012:1237), I come to understand why most of the research participants indicate that they had to disclose that they are living with HIV to their families. This also supports Mandova and Chingombe’s (2013: 101) view of collective responsibility with African societies. The following account demonstrates various reasons leading to the disclosure of one’s HIV-positive status:

In the family, I see that it is better. In fact, I started to tell my child, the eldest one. So that as the eldest child, at times I might not wake up alive. ... I also told their relatives. I did that so that should there be some things that might become problematic in future, they are the people who will be in a position to get me treated. Even in the community, I told them. I told myself that you never know who might help you. Because I was there, left with the children alone. (Grandma Mecky)
One notable narrative on disclosure shows the extent to which people can go to evade blame. Grandma Shelly says that she disclosed her HIV status to her children because she did not want to be held responsible for being HIV-positive. She is fifty-six years old and only realised that she is HIV-positive at the age of fifty. As an older woman, she might want to evade ageism stereotypes that she is too old to have HIV, as reported in Emlet (2006: 781) while at the same time feeling humiliated to tell her children about it, as studies such as Emlet, Tangenberg and Siverson (2002: 237) point out. Her response is:

*I once wanted to ... have thoughts that children no-no [I must not tell them] ... But I later realised that it does not help in any way if I don’t come open with my children yet their father gave me the disease (HIV). So I got to the point of telling them. I didn’t want them to think that eer, maybe mummy eer, she went to look for the disease.* (Grandma Shelly)

Others, however, express their feeling to keep their HIV status known only to selected people. Since disclosure of a stigmatised condition is a difficult decision to take, it can be restricted (Rodkjaer, Sodemann, Ostergaard & Lomborg 2011: 3; Stutterheim, Bos, Pryor, Brands, Liebregts & Schaalman 2011: 382). Some research participants’ ways of disclosure are consistent with this finding. They limited their disclosure to only a selected few who mainly include family members:

*My children must know that I am sick not a next door [neighbour]. Next door [neighbour] does not work. ... Next door [neighbour] at times will go around spreading to other people that: “Do you know that this old woman has HIV!” I cannot tell her.* (Grandma Vicky)

The reality that disclosure of an HIV status is not easy and that most of the research participants struggled to come to terms with their HIV-positive condition resulted in the research participants taking their time to tell others. Mostly people fear stigma if their HIV status is known to others (Gilbert & Walker 2010: 143) as they are aware that HIV is associated with
socially undesirable behaviours like prostitution (East, Jackson, O’Brien, & Peters 2012: 15).

This corroborates with disclosure experiences of some of the research participants as indicated here:

*I kept it a secret! I did not say anything for long and then I later told her... It was hard to tell someone that this is what is there now ... I don’t want to lie, HIV is not something that is easy to tell people that you have. Especially those days. E-v-e-r-y-o-n-e who had it (HIV) is a prostitute what, what. So you cannot just stand there and tell people that I have it.* (Grandma Kate)

Others however delayed their disclosure because they felt that the time was not right for the recipients of the news:

*My child was still young, she was in grade 7. The reason is that, I realised that for the child to understand it, I must tell her at a point when she can understand it so that she can accept it.* (Grandma Mecky)

Nevertheless, others feel that telling someone that they are living with HIV depends on how they relate to each other, be it a friend or a relative. The conversation with Grandma Tamar shows that a person cannot just disclose her HIV status because she is obliged to do so by socially defined expectations. She feels that disclosing to people is conditional:

*It is right to be open to them after studying them (relatives). That, these people that I am telling this, how do they take it? Then you decide whether to tell them or not.* (Grandma Tamar)

This finding supports findings that disclosure is mostly contextual (Donahue, Dube, Dow, Umar & Van Rie 2012:1237).

As part of exploring the research participants’ emotions (existential feelings), I ask them about their post-disclosure feelings. The most significant finding is that the research participants felt
relieved after telling someone about their HIV status. Here are some of the most prominent responses:

* I f-e-l-t. You know, you will be carrying a heavy load, you know. There will be some things that will be heavy on you. So when you tell someone it seems as if you have unloaded that heavy stuff (laughs). So I felt very relieved. (Grandma Kate)

* Myself I felt very relieved because I was seeing as if I had a heavy burden on my shoulders. And each time I would say: “Must I tell her today or must I not”. “No, no, I will tell her tomorrow”. And when we get to that next day, I would say: “Must I tell her or not. Let me tell her another day”. (Grandma Mecky)

I also explore the respondents’ views on the reactions of the people to whom they had disclosed their HIV status. Here, I want to understand how other people’s reactions, especially husbands, impact on participants’ disclosure experiences as part of their social construction of reality. Their responses show that not all people react negatively to the news that one has HIV. Contrary to reports that women face violence and alienation upon disclosure of their HIV-positive status to their partners (Kasenga, Hurtig & Emmelin 2010: 33), Grandma Tamar, who earlier notes that she received news of an HIV diagnosis with ease because she understands that she is not the only one with HIV, receives support and encouragement after her disclosure to her husband. What sets her story apart from the rest is that she lives with a husband who is HIV-negative. This is a recount of her husband’s reaction after disclosing her HIV-positive diagnosis:

* He said: “Certainly”. He is the one who actually comforted me, he did not say anything bad about it. (Grandma Tamar)

There are some participants who made their disclosure to people who already knew or suspected that they have HIV. As a result of their reaction(s), the process of disclosure became a less hurtful one. My attention is focused on the bearing of age and gender on disclosure. Grandma
Maybe, diagnosed with HIV five years ago, tells me that her son, whom she first told about her HIV status, noticed and knew it before her. The son, however, could not tell her because he is just a child. Instead, he talked to his father and advised him to take the HIV test. Most probably, the son took strain to talk about his mother’s HIV-positive status, as noted in Emlet’s (2006: 781) work which underlines that conversations related to HIV with older children are difficult. This difficulty arises from the reality that most cultures limit conversations on sexuality as mentioned in Emlet, Tangenberg and Siverson’s (2002: 237) study. Grandma Maybe’s grown up son felt that he is not in a position to tell his mother about his suspicions that she has HIV. Here is how she narrates this:

*I can say he (son) is the one who first gave me counselling. He understands me and he told me that: “Mother I saw it long ago that you are now sick (HIV-positive). But as a child it was not possible for me to tell you first”.*

(Grandma Maybe)

In the case of Grandma Kate, there was relief in that the disclosure of an HIV status yielded a non-judgemental reaction, as her sister already knew that she has HIV:

*I think she is the one who first knew about it. So when I told her she just said: “N-o-o its o-o-k”. But you could actually tell that she had known it for long. ... In fact she made it easy for me because she expected it. So she did not say: “Hee, what happened what, what?”* (Grandma Kate)

Other recipients of the news, however, reacted with anxiety and concern. In Grandma Mecky’s case, her daughter’s concern relates to the fact that she had lost her father to an AIDS-related illness and she was sick at that time. As a result, the child’s worry led her to seek a further understanding of the HIV and AIDS relationship because her father had died of AIDS earlier and by then her mother was telling her that she is HIV-positive. Her concern relates to the fear of losing both parents, a common occurrence that time, as indicated in the following quote:
Aah, that time I told her. It was the time when I was not feeling well. ... I remember she asked me that: “So is HIV and AIDS the same thing?” ... At that time, the parents would both die at the same time. So she thought that since her father had died, mummy was also dying. (Grandma Mecky)

As a sub-theme on post diagnosis, I explore the consciousness of research participants in relation to the fact that they are living with HIV as older adults. Consciousness, as discussed in the theory chapter, can be constructed negatively through fear and expectations of what a person projects in his or her mind (Searle 1983: 1; Zhou 2010: 311). This projection is based on the social stigmatisation of people with what is seen to be an undesirable condition. The research participants’ actions at some point, reveal how self-conscious they felt owing to suspicions that they are living with a socially undesirable health condition, such as HIV. Some intentionally directed their efforts to disguise HIV symptoms and others felt very uncomfortable to face people. Disguise, avoidance and social isolation, are common mal-adaptive strategies that people employ (McIntosh & Rosselli 2012: 2147) to avoid perceived stigma, especially when HIV symptoms become too visible (Stutterheim, Bos, Pryor, Brands, Liebregts & Schaalmam 2011: 382). Grandma Jessy admits that she did not even want people to visit and see her while she endured troublesome HIV symptoms, owing to the fear of people’s negative reactions. The following extracts represent how some of the participants’ condition dictated their actions:

*It affected me a lot. That is what made me not to go outside to face other people. I used to stay inside [the house] alone, locking myself inside the house. Even the pills (ARVs), I used to take them at a clinic far away, where familiar people would not see me. Because I was afraid that people were going to laugh at me [and] even that [people would] neglect [me]. … Even going to church, I stopped going to church. I preferred to stay alone in the house.* (Grandma Jessy)

*I was once concerned about it such that for a long time I was wearing dresses with long sleeves* (to cover-up skin irritations on her arms). (Grandma Mecky)
The findings reveal that the women’s concern with keeping their HIV status from other people is finally cast away after a period of time. Grandma Jessy — the one who did not want people to visit her while sick, now gives testimony to others that things can get better if they seek medical help. This is consistent with Russell and Seeley’s (2010: 375) finding that, with time, a person reaches a turning point where she or he changes her or his perceptions from being HIV positive to being positive about HIV. This is what Grandma Jessy says in response to the question about whether there are other people who know about her HIV status besides her sister:

Many, many people because I no longer keep it a secret. I talk to many people and give them an example that I was once like that (frail). Now I am like this (healthy). Look at me now. (Grandma Jessy)

Further analysis of the research participants’ experiences under the post-diagnosis theme is done in an effort to fulfill one of the research objectives of examining the extent to which society's portrayals of HIV influence the subjective thoughts and actions of the research participants. The interviews explore the experiences of research participants in relation to how society perceives or socially construct HIV and those who are infected with it. I asked participants about what they know about or hear from people with regard to people who are living with HIV. They note that there are a variety of stigmatising names that people call them.

A further probing on their feelings towards these nicknames reveals that not one participant narrated having reacted to these with unhappiness. They are not worried about the people’s prejudice and stigmas. Their stories compel me to believe that although these women are taught to manage such situations at the support group, the maturity and wisdom that comes along with age (Siegel, Raveis & Karus 1998: 686) also plays a part in shaping their attitudes towards these stigmatising names. Grandma Kate actually laughs about this issue as we were
conversing and I wonder if I would get the same reaction from a twenty year old HIV-positive woman or had I interviewed her when she was younger. Apparently, some of the names are taken by the participants as a motivation to live positively as they do not allow the derogatory nicknames to affect them. As a result, instead of feeling offended, they take it in a positive way. Here is what some research participants have to say:

*Yes, but people used to say things long back. Aah, long ago in the 2000s, people used to talk. They said: ‘Best-before’ this and that. ... Aah, there is nothing I can do. I just say we will meet one day. Myself these days, I now know that it is better to be called a ‘Best-before’ because I know my [HIV] status. How about that person? Maybe she doesn’t even know her status and yet she can be a ‘Best-before’. (Grandma Kate)*

*There is someone who once gave me this name. Calling me a ‘Zhing Zhong’ (laughs) (Zhing Zhong is a nickname most people in Zimbabwe give to cheap Chinese products that are not durable). Ha-a-a the ‘Zhing Zhongs’. You see ... But we never put that into our minds. Because you can see that it is better because there is treatment for us. (Grandma Shelly)*

An interesting element emerging from my conversation on stigma with Grandma Maybe is that some people do not stigmatise her because they know that she contracted HIV as a victim and not out of her volition. I gather from the conversation that she is of the assumption that blame is behind stigma — implying that people stigmatise those with HIV because they feel that they deserve that treatment. Grandma Maybe’s version of non-stigma experiences corroborates Muturi and An’s (2010: 396) view that people can empathise with those whom they consider as innocent victims of HIV. My understanding of this, which also draws on views by scholars such as Mawadza (2004: 420) and Svensson (2014: 569) is that people still hold the perception that HIV is a punishable condition brought down on those with detestable sexual morals. Here is what Grandma Maybe says in reaction to my question about whether there have been any feelings or experiences of stigma from the people who know about her HIV status:

*Haa, nothing as such ... I just live my life like that. Maybe it is because I did not publish to many people that this is what is there (HIV-positive). Plus, you*
see, if people know how the disease (HIV) came to you, they do not treat you roughly because they know that this person, the disease was just brought to her you see… It is now different from those people who know that this person, aah, has many friends (sexual partners). Or what we see other cross borders doing: that here they have a husband, in South Africa they have another. People will not respect you. They will blame you because they say it is your fault. Yes, you got the disease by yourself. (Grandma Maybe)

All in all, most of the research participants did not initially take their HIV diagnosis well but later recovered and managed to live with it. What captures my attention is the way the women respondents narrate their experiences of trying times but did not show how they were being adversely affected by these experiences. In the case of Grandma Mecky, her brother to whom she had entrusted the custody of her children, passed away. She tells me that part of her strength comes from the fact that she has HIV but is still alive. Others, like her brother, died even though they did not have HIV. As a result, most of the research participants view themselves as conquerors and champions against HIV.

4.3 Adapting and adjusting to the condition

This third sub-section of data analysis presents themes on meaning-making as research participants try to make sense of the issues that relate to their condition. It also discusses the positive developments or post-traumatic growth that come about as a result of experiencing a stressful encounter (refer to section 2.4.2, pg.48). The most prominent finding in this regard is that, with time, research participants subjectively accepted their condition and have created new meanings in their lives. They are trying to create and maintain social order by turning negativity into positivity so that they can continue to fit into society irrespective of the fact that the same society sometimes ridicules them because of their HIV status. The research participants all went through a process of adapting and adjusting to living positively with HIV into old age.
Themes in this section focus on the participants’ experiences as they accept, manage and understand their condition.

The findings of this research suggest that these women have acquired the ability to live with HIV into old age. Their narratives show that they are empowered to live well and be in control of their lives. Most of them have been living with HIV for quite some time and made some self-enhancing changes in their lives, which include having a positive physical and mental health. People who are living with HIV usually undergo a transformation process in which they initially struggle to cope with, then proceed to accept their condition and eventually reach the point of taking charge of their lives (Tsarenko & Polonsky 2011: 465). This scenario applies to the research participants who admit that they initially could not come to terms with an HIV diagnosis but later accepted it and are, during the time of the research, living harmoniously with a ‘chronic stressor’. They adopt the “in-order to” and the “because” motives (see chapter 1, section 1.2.1.3, pg.18) to live well with challenging circumstances. They even narrated painful experiences without expressing sorrow as shown in the following excerpt where one of the participants laughed while narrating how she was so hurt that she scolded her husband after being confirmed HIV-positive:

*It hurts. Why can’t you scold a person like that?* (laughing) (Grandma Kate).

### 4.3.1 Understanding the condition

It is clear that the research participants understand the many implications of growing old with HIV. They developed positive mental and physical competences which are spurred by an understanding of their condition. This kind of growth, referred to as post-traumatic growth, is reported in most people who live with a chronic stressor for longer periods — as documented
in Sawyer, Ayers and Field (2010). Most of these women, including those who once tried to conceal their HIV symptoms and status, are no longer ashamed to talk about their positive HIV status. With the passage of time, support and the proper management of HIV, they reveal that they can now openly talk about HIV to anyone. The study participants understand HIV and believe that, as conquerors, they can inspire others to embrace HIV and get the necessary help. These women tell me that they use their present physical appearance to convince people that help and life exist when you seek them. None of the research participants looks sickly. Some like Grandmas Vicky (61 years old) and Rose (50 years old) even challenged me in the following way: “Would you tell that I have HIV if I hadn’t told you?” Grandma Mecky is now a strong public HIV activist, and others advocate at a micro-level:

> Sometimes I am called to speak at many gatherings where I teach people only about HIV. And it’s helping a lot of people. Many people are being helped and you can actually see that the community is changing its attitude towards people with HIV. You can actually see the difference from those days in the beginning [of the HIV/AIDS epidemic]. (Grandma Mecky)

> I will be doing it (counselling) to make people get help because I know how a person can suffer [because of HIV]. ... In fact I first tell them to get tested first. I will be doing that to make other people get help because some are still living in denial. You can see a person lying but you can tell that this person needs some help, yes. (Grandma Jessy)

In addition, the influence of age on all these endeavours is reflected in some of the participants’ stories. Some consider themselves ‘seniors’ because of the period that they have been living with HIV. It is this seniority status that gives them the confidence to talk to other people on the assumption that they will be listened to because they are elders:

> ... now we are the seniors. W-e-e are now counselling others. If we see them doing this and that then we can tell them that: ”My friend run, go and get tested now and get treatment”’. (Grandma Kate)
In trying to understand their condition, research participants compare HIV to other sicknesses. They feel that ‘their HIV’ is better than other sicknesses and would not want to be treated differently from other patients. They realise that other medical conditions can be far more challenging to live with than HIV:

*Just tell yourself that: “I am just like other people, other sick people with [sugar] diabetes or BP (high blood pressure)”. A person with sugar [diabetes] is living even for over 30 years with that sugar [condition]. How about you? You can live a long life also with the disease (HIV).* (Grandma Tamar)

*And otherwise if you want to see: the one who has sugar [diabetes] can be more serious than me because sugar [diabetes] can go high anytime. Even the one with asthma, it just gets worse any time.* (Grandma Shelly)

Understanding one’s condition can be dependent on how the ‘sufferer’ interacts with other people as is common in many lifeworlds where people relate intersubjectively. For example, Grandma Kate tells me that she is at home with living with HIV because she understands that it is affecting and infecting many people everywhere in the world:

*As time went on, aah, I ended up saying eee, these things (HIV and AIDS) seem to be everywhere in the world. This is what is there now (I am now HIV-positive) and I accepted it.* (Grandma Kate)

Others now understand that anyone can be a victim of HIV and death is inevitable for everyone as narrated by the following participants:

*… it affects me a bit but I will tell myself that it is not my fault. It’s something that just came to me. It (HIV) came to me whether I liked it or not. It can come to anyone.* (Grandma Maybe)

*Eer, during the first days it was very painful to me. But these days I have learnt to accept it as it is. Because no matter what sickness a person has, its ‘Masofa panze’ (sofas outside - to indicate that there is a funeral). There is no person who is going to live here on this earth forever.* (Grandma Mecky)
Viewing HIV as a blessing in disguise is another way that is helping research participants to adapt and adjust to living with HIV into old age. While most people view HIV as a death sentence or a pathway to a life of complications, these women’s attitude towards their condition is worth noting. Some feel strongly that HIV has opened better life opportunities for them. As is consistent with such post-traumatic growth, they have managed to access resources that improve their wellbeing as noted by Watkins-Hayes, Pittman-Gay and Beaman (2012: 2029). Grandma Mecky, who is openly living with HIV, is one such person whose experience of living with HIV has taken her from a lower to an upper level in life. This is how she feels about living with HIV:

*Myself, through HIV, I have seen places that I have never been to. Places that I never thought I could get to them because of this exposure and disclosure that I do. Sometimes I give my testimony. Sometimes I do this and that. Then I later hear that some people want me to speak at their gathering or: “Come here, we want you to represent us here”. So right now, I represent people who are living with HIV in Harare (the capital city of Zimbabwe). So I sometimes go out and get into hotels, giving presentations on HIV and how I live with it – my challenges and all that. So I can actually see that HIV has afforded me an opportunity to reach a level that I never reached – a level higher than what I used to be. And HIV actually enabled me to live healthy. Rather than if I had kept it to myself I would have died long back. Also my relationships with other people got stronger because of HIV. Here at times, when you get here, you will see that within a few minutes somebody gets here. After a few minutes, another person comes in. People now come here.*

(Grandma Mecky)

Grandma Jessy, who once could not afford medication for her dying family members, used the situation as a motivation to educate herself and acquire skills that make her self-sufficient because she does not want to be pitied as a result of her HIV status. As such, she went back to high school and attained an “Ordinary” level qualification and did a sewing course. This is how she recounts her story:

*I can say I went up to form 4. That I did when I was old like this. And I also did a course, a sewing course later when I am old like this. ... I realised that life is better if you work for yourself instead of saying today people help me, tomorrow people help me because you have HIV. Even at
the support groups we are taught to do things for ourselves. (Grandma Jessy)

Part of understanding one’s condition involves acknowledging the difficulties that one faces and finding ways to navigate through a life with challenges. Some research participants admit that the journey to accepting their condition and not bothering about what people do or say was not an easy one. They had unpleasant encounters that made them feel humiliated. I discussed in the theory chapter (see section 1.2.1, pg.11) that one’s lifeworld is part of the broader socially constructed world of everyday reality. As such, one can be impeded of free-will because of the different perceptions that people hold (Schutz & Luckmann 1973: 4). Therefore, there are challenges in the lifeworld experiences because the lifeworld consists of different people with different perceptions. As a result, some of the research participants experienced enacted stigma. Grandma Jessy and Grandma Kate had to join other churches because of incidences of stigma at their former churches as the following quotes highlight:

*It happened where we used to stay, at the church where I used to go. I ended up leaving that church to find another one where people did not know me well. If it was at the parties where we used to go, they would neglect you. If you go to the pots to try and cook, people did not like it. If you touch their pots or if you touch their food they did not like it. (Grandma Jessy)*

*Aah, in the first days it used to happen, happening for sure, especially at the church. At the churches there, that is where the main problem was. T-h-a-t even when people are being allocated duties, eee, you would hear them say: “This one no, wait, don’t let her do anything”. … When you go there (church) they would say: “AIDS this AIDS that”. And I said: “Eee, let me just leave this church and get a new one where I am not known”. … Even if you say you wanted to join the choir, they would give you excuses, this and that. (Grandma Kate)*

The situation is however not the same for Grandma Mecky who is an active member and HIV activist at her church. She narrates that her church received her well despite her condition:
I am very happy that I was well received in my church even though I am sick (HIV-positive) like this. But my Reverend, I spoke to him. I spoke to him about this and he accepted me as I am. (Grandma Mecky)

In summary, an analysis of the research participants’ experiences on how they understand their condition reveals that it can both be individualistic and intersubjective. As part of meaning-making, research participants understand their condition and have developed a high sense of discernment that assists them to adopt relevant and useful things to maintain their wellbeing. The research participants developed a positive outlook about life by comparing HIV with other chronic medical conditions and then point out that their situation is not as bad as people think. In addition, living with HIV for a long time has promoted some post-traumatic growth that sustains the participants every day as they demonstrate a high level of positive mental health.

4.3.2 Accepting the condition

All the participants report that they accept the fact that they are living with HIV for the rest of their lives. Research participants indicate that they became reconciled with this situation mainly because of the support they receive(d) and the realisation that they cannot change this particular health condition. The most common statement from their narratives is that: “I accepted that this is what I am now.” Research participants, over time, attuned their perceptions, thoughts and feelings to develop a positive attitude towards a condition they cannot change. Most of them mourned and grieved over the reality of having a chronic medical condition but eventually reached a point of acceptance. This supports previous studies that posit that as people live long with HIV, they are more likely to accept their HIV-positive status (Baumgartner & David 2009: 1730). Here are the most significant examples to illustrate this point:
I have lived long with the disease (HIV). I don’t care anymore because there is nothing that is going to change. I know that nothing is going to change and I have accepted it. (Grandma Rose)

I accepted it and I now understand what I am (HIV-positive). ... So it affected me but then I later got to the point when I told myself that there is nothing to do anymore. Then I accepted it. (Grandma Maybe)

It is evident from the participants’ narratives that it took time for them to accept that they are living with HIV. What draws attention the most is the way the research participants express themselves. They talk about accepting the condition as if it is something that can happen overnight. They brush over the low points they went through due to the HIV diagnosis and courageously talk about how they are no longer bothered about people’s negative reactions. They were even not emotional when talking about the hurtful encounters. In fact, all my interviews went through without any emotional breakdowns although the subject involves sensitive issues. I understand that the research participants, as older adults, want to portray a socially desirable image of themselves. The participants are also empowered by the proper and constructive language received from the support groups they are affiliated with, which enables them to display a positive image of HIV to the society as part of their HIV management. This, I believe suppresses their memory to selectively retrieve the fittingly less traumatic details of what happened during the early stages of the HIV condition.

I understand from the research participants’ narratives that the process of accepting their condition involves love, care and compassion. The research participants’ attempts at embracing their ‘self’ and constructing a positive sense of their condition enable them to establish new networks of friends who are also living with HIV. They reveal that they want to involve people who accept them and are not prejudicial towards their condition. Although such networks are arguably fragile and short-lived (Emlet, Gusz, & Dumont 2003: 46), these women
show that they are content with their ‘like me friends’. The study participants hold the perception that their HIV-positive friends understand them and are not judgemental of their condition because they live with similar conditions. Some are even of the opinion that, as a person who is living with HIV, they must find a partner who is also HIV-positive to engage in a sexual relationship. They perceive that compassion and support comes from somebody who shares characteristics that are similar to those in their lifeworld:

*I don’t have a friend that I can say I talk to but for these friends of mine in the [support] group that I am with. Like these ones that I take tablets (ARVs) with. We can talk to each other without any problems because we are all the same. And it is easy for me to talk to them because what they have (HIV) is the same as what I have. So there is no one who says: “I don’t have the disease (HIV)”. (Grandma Vicky)*

*Yes, someone (sexual partner) who is also in the programme (ART) because your [social] network is not, not a problem. “Partner let’s take a condom”. You are what now? Using the condom. “Partner today it’s like this”. He understands because he is living in it. (Grandma Tamar)*

One significant finding concerning social networks and the general social life of research participants is that some of them maintain their previous networks because people are not aware that they are HIV-positive. In the case of Grandma Maybe, she accepts her condition but is afraid that other people will not accept her. As a result, she disclosed her HIV status to a selected few. Grandma Vicky similarly says that people at her church treat her equally like other people because they do not know that she is HIV-positive. This substantiates Campbell, Skovdal, Mupambireyi and Gregson’s (2010: 978) findings that stigma is mostly driven by fear of contagion and moral judgement. Generally, research participants feel that the process of accepting their condition can be disturbed if people accept them conditionally and give them a qualified approval to fit in the social world. This is how one of them responds to the question on whether there are some relationships that were affected because of her HIV-positive status or her age:
At church haa, nothing happened. Because most of them do not know that I have the disease (HIV) because I did not tell them. So we just do our things just like that. As if no one has the disease. (Grandma Vicky)

A further consideration of the significance of social networks in assisting the participants to both adapt and adjust to the HIV condition shows that they also experience a breakdown of some of their relationships. Grandma Kate recounts the difficult process of separating herself from her husband’s family because they were accusing her of killing her husband who had died of an AIDS-related illness:

*That time we were staying in the rural areas* in (name of place withheld for anonymity purposes), *so because of disagreements with his relatives I then decided to come over and stay here in town.* (Grandma Kate)

Summing up, the research participants demonstrate a high level of self-acceptance by embracing themselves despite all the fragilities that they may face. This in turn enables them to accept and live with HIV into old age with less difficulty. Love, compassion and unconditional acceptance are key to the process of establishing new networks. Clearly, the participants now disregard some of the impediments associated with an HIV-positive status as they adapt and adjust to living with it.

### 4.3.3 Managing the condition

The analysis in this section focuses mainly on the rational actions that research participants engage in to manage their condition. As discussed in the theory chapter (see section 1.2.1.1, pg.12), people can orient actions and adopt rational motives to suit a problematic situation (Schutz & Luckmann 1973: 21; Hughes & Sharrock 1980: 1). This enables people to create new meanings in the face of challenges as they try to make sense of their situation. The research
participants report that they are doing all they can to deal with the fact that they are ageing with 
HIV. It is evident from their narratives that they have developed the ability to live in harmony 
with their positive HIV status. They however acknowledge that it is not any easy task. The 
research participants express their concerns over difficulties in life, which include harsh 
economic factors, dealing with HIV symptoms, having to negotiate side effects from the 
treatment, and the general challenges brought along by ageing. These issues are present in 
many of the participants’ narratives about their experiences of ageing with HIV. Although 
some studies, such as Schatz and Gilbert (2014: 778) report some age-related physical 
challenges among older people, these women report challenges that particularly relate to their 
HIV-affected lifeworld. The following extracts are representative:

*Where we get our medicines at this clinic, these are the problems of the economy we have in Zimbabwe. At times you will not have salt in the house yet the next day is the date you are supposed to get the medicine (ARVs).* (Grandma Rose)

*It is painful. Eer, HIV is painful. ... That right now we are on treatment, we are just winding time because inside it is painful. At times you wake up feeling this other pain that you cannot understand...* (Grandma Mecky)

Despite these setbacks, the research participants report that the available social and structural 
resources enable them to have control and live with the ‘chronic stressor’ into old age. The 
findings reveal that research participants are living positively with HIV and have typified 
certain actions to add quality to their lives. They are selective about what they eat, some engage 
in regular exercises, adhere to the required HIV medication, seek medical attention when they 
feel sick and take care of their psychological well-being. They all practice this in order to get 
r rid of any markers that might discredit them in the eyes of others, and that potentially results 
in them becoming misfits in society. They demonstrate what Siegel, Raveis and Karus (1998: 
686) term as the respect for health and life that comes with aging. It also confirms Emlet,
Tozay and Raveis’ (2010: 4) observation that older people who are living with HIV practice self-control and care in managing their condition. The following quotes explain how research participants internalise and habituate recipes for survival:

*We were told that you must take them (ARVs) on time and you must eat healthy food and rest. You must no longer do a lot of work. Just work reasonably. And also you must exercise your body. So I am following all the things that we were told at the clinic.* (Grandma Vicky)

*The most important thing is to know your time of taking your pills ... and food, your food. If you are going to other people’s homes where you are not free to tell them what you want, go with your own lunch box in your bag or in your handbag. Put your buns inside and go with them. When you want to take your pills just take your buns, take your water and then kadakakadakada (mimicking the sound of a pill being swallowed down with water). By the time they want to serve you food, you would have what, taken your pill already at your [usual] time.* (Grandma Tamar)

Grandma Tamar also touches on a very sensitive matter regarding hospitality and health in the Zimbabwean culture. Culturally, a visitor humbly accepts things (especially food) offered to them by their generous host. There is even a Shona proverb that says “Hukama igasva, hunozadziswa nekudya”, which literally means that relations are half fulfilled unless one has eaten the food offered by the host. In her narrative, Grandma Tamar indicates that a person must defend her health by not accepting everything that she is offered when she visits. Her sentiments lead me to understand that such boldness is possible when a person is mature enough to stand her ground and has lived with HIV long enough to understand things that compromise her condition. Here are some participants’ views regarding this:

*Don’t let other people force you to eat things that are not good for you. Because when I visit, those spices, we are not allowed to eat them. But others will eat spiced food because they are shy. Don’t be shy. [With] these things (HIV) you cannot be shy. You need to be open. That, personally eee, things with spices I do not eat. Myself you can give me okra. It’s ok. Even those dried veggies, it’s ok, I can eat them. Even though the spiced meat is there. Tell them openly and freely. And if you see that it is difficult for you, don’t go there. Stay at your place because you know that this is what I am.* (Grandma Tamar)
Even beer, that beer that is brewed in rural areas for traditional purposes, I don’t do (drink) such things. At times you are told that everyone must drink it and if you refuse they say, “Hee, she is refusing to drink the traditional beer, who does she think she is? H-e-e, she must be punished”. (Grandma Kate)

I establish from the narratives that all participants do not use any other form of treatment other than the prescribed allopathic HIV medication. As mature people who understand their condition well, they do not use forms of treatment other than the prescribed HIV medication as highlighted in this quote below:

Myself I no longer use such things other than the ARVs. I used to use that stuff, what do we call it? Moringa (plant consumed for its nutritional and medicinal value). I would eat it, haa. I later realized that hey, even the doctor told me that you are mixing things and you are damaging your body. Do not mix things. It is better to take only ARVs. They are strong on their own. (Grandma Kate)

Another integral part of the participants’ management of their condition involves an awareness of the psychological affects that HIV poses on one’s health. Some of the research participants are knowledgeable about things that affect their psychological wellbeing as they age with HIV. They describe how they refrain from issues that compromise their immunity. In one of the conversations, a grandmother sent away her grandchild because she was naughty. She chose not to live with her grandchild because her alleged problematic behaviour would impose negative effects on her immune system. Nevertheless, the social and Zimbabwean traditional expectations are that a grandmother should take care of grandchildren, especially in cases where the parents are unable to do so. A grandmother, in the Zimbabwean culture, can adopt a grandchild to stay with to combat loneliness at old age as reported in Sun, De Florio, Gui and Blondia (2014: 5), or to avoid “an empty nest syndrome” as it is termed by Van Manen (1990: 187). This grandmother thus acted against the social norm in order to preserve her health:
I once stayed with one of them (grandchildren). So she started to get very mischievous. So, as a grandmother I saw that my CD4 will decrease. Even the boys said: “Aah mummy, to stay with that naughty child no, your CD4 will decline. It’s better we send her to her family”. (Grandma Rose)

Another participant describes the importance of not entertaining negative thoughts that are counter-productive in managing HIV:

_To just live without thinking about it. Yaa, not to think too much about it every time. That everywhere you are you think about it, No-no. Don’t get concerned by it. That this AIDS, when is it going to end?_ (Grandma Tamar)

The research participants indicate further that they manage their condition well and tolerate the stigmas associated with living with HIV. They show little concern about people’s unconstructive reactions to their condition. A common reaction among people who are living with a stigmatised social marker, such as HIV, is to constantly worry about negative public attitudes, as highlighted by Varni, Miller, McCuin and Solomon (2012: 130). The women under study here were only concerned about HIV while still trying to come to terms with being HIV-positive. With time and also with the influence of age, they made a complete change of attitude and began to disallow pessimism to interfere with their choice to live happier and healthier. The adjustment of their mind-set results in the transformation of negativity into positivity. It is clear from the research participants’ narratives that the stigma and discrimination directed at them also motivates them to live positively. The following response is one of the common ones to the question about their feelings regarding negative reactions:

_I don’t care about it. I actually feel happy and I tell them there and there that, “Look here I am recharging (taking ARVs). But you are not recharging. But you are walking around feeling sick. Why can’t you go and find out what is making you sick?”_ (Grandma Jessy)
All the research participants report that their conditions are better, especially with the ARVs having a positive effect on their health. They are living without any worrying physical symptoms of HIV and have regained their physical well-being. ARVs boost their will to live and assisted the participants to reconstruct and live their lives meaningfully. Hence, they have new meanings to their lives and are feeling good about themselves. Creating such new meanings is proof that these women choose what is relevant to them and readjust their priorities to deal with challenges in their lifeworlds:

*Hey! It was terrible: a light person, I became black. My hair, I had it cut. My mother insisted that I keep a hat on my head. My hair was thin but now when I started to take the ARVs my hair grew back and it is now long. Even longer than those without the disease (touching her uncovered and neatly plaited hair). Those pills. We thank God for them because my body is back and I am feeling very strong. If I didn’t tell you that I have the virus, you were not going to suspect it. Am I lying? (Grandma Rose)*

Another noteworthy result regarding the participants’ management of their condition relates to the reluctance, by some, to engage with sexual partners who compromise their health and wellbeing as a whole. Besides the fact that sexual activity decrease with age (Emlet, Tangenberg & Siverson 2002: 237), these older research participants understand that HIV can spread through sexual contact and that it can be difficult for a woman to prevent the sexual transmission of HIV. Grandma Jessy narrates that she stopped dating men because they were stressing her as they refused to wear condoms:

*Eee, I used to have these friends (sexual partners) and I did not find it helpful. I saw that it was stressing me. They gave me so many problems so I left them. You will see that you are living someone else’s life, doing e-very-t-h-i-n-g that he likes and not what I want. We never agreed on anything, especially condoms. Haa, it was a struggle. I am now living on my own. (Grandma Jessy)*
Furthermore, most of the research participants hold the perception that since they contracted HIV sexually from their husbands, they would rather abstain from any further sexual activities. Some of the responses also expose some level of bitterness towards men. Nevertheless, they also seem to harbour a desire to avoid sexual relationships in an effort to avoid likely negative effects in the management of their condition. They report that they only want to focus on their status as HIV-positive widows and hence, prefer celibacy. This is evident in this response:

But one thing that I signed for myself is that I do not want any other thing called what, called a man. No. We are told in our [support] groups that you can. You can do it with another person. But myself I said it is difficult for me. What I got I got. It’s enough ... That I got HIV through meeting a man (sex), then I go again. No! (Grandma Rose)

It is also interesting that while participants such as Grandma Mecky and Grandma Tamar advocate for the use of condoms as a preventive measure, some feel that condoms are not for people their age. They have a shared ideology that when you are old, you engage less in sexual activities and cannot use condoms. As noted earlier, some feel that, as widows, there is not much left for them except celibacy. The research participants repeatedly mention that as widows, they are just ‘staying’ like that, thus suggesting that they are abstaining from sex since their husbands died. Their society expects an un-inherited widowed older woman to refrain from sexual activities, hence research participants construct their reality based on such perceptions and beliefs. This expectation speaks to the view that social reality is socially constructed in people’s minds (Lincoln & Guba 1986: 77). This is one such example:

... on prevention, I can say that if you are a woman eer. ... Especially us widows. That eer, this is what we are, yes. What we only want is food to feed us. For those other people who are younger, those are the ones I can say must use what, condoms. (Grandma Shelly)
In another notable conversation, a participant who lost her husband two years prior to the research, expresses contradiction to such ageist and sexist stereotypes towards condoms. She feels that if her husband was still alive, they would be using condoms:

*Even if my husband was still alive, we would just say he lives with his disease and I live with mine. Not to mix. Or that if we use condoms, he would use his, while I use my own. Then we would live like that.* (Grandma Maybe)

I realise, from my conversation with Grandma Maybe that men also feel that they must not spread HIV to their wives. This is shown in a story that she narrates, which on the surface seems irrelevant to HIV prevention. But her story indicates a subtle feeling that some men can develop a fear of transmitting the virus to their wives. Her husband refused to have sex with her after taking an HIV test and finding out that he is HIV infected. What is interesting and relevant to the gendered life that most women experience is the way Grandma Maybe took her husband’s reaction. She just obeyed his orders and tolerated his seemingly unusual actions without challenging him. This points to the fact that married women are often passive in sexual relationships and not assertive enough to question a husband’s sexual behaviour. Passiveness in sexual issues is a social reality in many Zimbabwean societies as reported by Shoko (2013: 21). In this case, Grandma Maybe just said, “it is ok” and had unanswered questions that she later got answers on after testing positive for HIV with her husband:

*So on the day I came back, I was happy to be with my husband as somebody who was away for a long time. ... So my husband then told me that: “NO, NO, NO, today we are not sleeping together (having sex), I am not feeling well”. I then said: “It’s ok”. I did not think of any other thing that might be a problem. The following day is the one he travelled to (name of place withheld for anonymity purposes). So it troubled me that we had 3 months of not meeting (having sex). So what is the problem now? So after going for testing, I then knew that this was what it meant.* (Grandma Maybe)
In addition, the research participants express their willingness to contain HIV. They are conscious of the infectious nature of HIV and are precautious about spreading it to other people. Some of the participants’ expressions place HIV and ageing into the spotlight in that they reveal the limits in the social roles that grandmothers are expected to perform in society. They point out that there are nurturing roles they have to perform to their grandchildren, but they can no longer do them because of HIV. Grandma Maybe and Grandma Kate’s narrations exemplify this:

_When it comes to food, I know that I am sick (HIV-positive). So I have to eat my food. It is no longer possible for me to bite and spit for my grandchildren (traditionally grandparents prepare the food for babies sometimes by way of masticating it before feeding the child). (Grandma Maybe)_

_I now know that it is no longer safe to do that. Or that I suck a freezit (ice-lolly packed in a plastic sachet) and spit it into her (small child) mouth. Or even a sweet, a lollipop that I am sucking. If she asks me for it, I cannot give her. (Grandma Kate)_

Some are relieved that their age saves them from any suspicions of being HIV-positive. It is clear from my conversation with Grandma Vicky that some people still associate HIV with a certain age. She points out that people do not suspect that she has HIV because she is an old person and looks very fit just like any other person. The fact that there is an intersubjectivity of interactions and thoughts in a society where people end up constructing reality basing on shared beliefs (see chapter 1, section 1.2.3, pg.22) leads some of the research participants to believe stereotypical ageism assumptions that their HIV status and age are not compatible. In this case they view this ageism stereotype in a very positive way as it frees them from prejudicial reactions from society. Thus, the fact that people associate HIV with younger people is a relief to some participants as this shields them from the double stigma relating to old age and HIV – a double stigma that old people with HIV are likely to face. It also protects
their social networks as people continue to associate with them without any suspicion of HIV as highlighted earlier. This is how one of the participants describes her situation:

... Eer, if you have not yet told a person that you have HIV, that person cannot see it. And with my age they would not suspect it that I have HIV. If you (Interviewer) say you have HIV, they believe you without a problem. But they will not suspect anything [on me] unless if I tell them. (Grandma Vicky)

However, some admit that being HIV-positive at their age can be a concern. People often view old people as free from sexually transmitted infections and find it difficult to accept that an old woman can have HIV. This is a representative response to the question on the nature of life experiences of an older person living with HIV in their community:

Aah, life for an older person like me: Here, it’s life that is very hard. Because to an older person in this area, life is very difficult. Because sometimes a person does not accept it that this is what you are. That you have HIV because you are now an old person. (Grandma Mecky)

I analyse further the research participants’ experiences as they go through what we may call ‘an HIV and age challenged life’. The narratives confirm that they receive support in their management of the HIV condition. They have a good support network which assists them to accept and thrive with their condition as they incorporate HIV into their everyday lives. All participants belong to a support group for various reasons, including psychological sustenance. In addition, they managed to restructure their lives through support from various other people, thus confirming reports stating that social support is a source of strength for most people who are living with HIV (van Dam, van der Horst, Knoops, Ryckman, Crebolder & van der Bart 2005: 2). Here is how some of the research participants narrate their stories of support:

My mother accepted it. Nothing troubled me because she saw how sick I was at the time. She is the one who took care of me big time. She did not
feel disgusted by me. ... especially that time I was sick with TB. My mother did everything whole-heartedly. She washed everything. She opened the windows for fresh air to take away the air with TB. (Grandma Shelly)

The people at the clinic noticed that I was struggling with that. So they kept on coming to visit me for counselling up to the time when I accepted it. And then I joined the support group FASO (Family AIDS Support Organisation). (Grandma Mecky)

Another fundamental part of managing their condition relates to having adequate supplies to meet their needs. All the research participants report that they engage in self-sustaining work for their survival. As adults, they express the need for self-reliance and show that they are in control of their lives as is expected by society. They express their unwillingness to be adult dependants as theory suggest in Keyes (2014: 8). For example, they say they can sacrifice other things in order to have the service fee they pay at the clinic each time they collect their ARVs:

*I prefer to suffer or to borrow food while I keep that $2.* (Grandma Rose)

The research participants also engage in subsistence agriculture in order to have enough food for their families. Instead of getting stories of poverty and starvation, I got success stories about how the women ‘use their hands’ to support themselves and other dependants under their care. The participants have been working for their whole life (some as cross-border traders) to provide for their families and find it hard to surrender to the demands of age combined with HIV. The following quote captures this:

*You have to use your hands – what must I sell that people want? Am I farming? What I have planted, is it enough for the year. Or where I am right now, the garden that I have, does it support me enough? All these you need to know.* (Grandma Tamar)
The aspect of gender roles also comes into the spotlight as all participants express the need to support their families. They mention the burden that they have as mothers to cater for the family. This confirms that the burden of care lies primarily on the shoulders of women as reported in the literature review (Poku 2005: 99). In addition, all of them, except for one, are now widows and thus play double roles of being a mother and a father. This, however, comes with negative implications as they overwork and compromise their health:

*Here I am – a mother. I am supposed to be doing all this: caring for the family. At the same time I have to take my pills (ARVs) because they have time. They need you to sleep, to rest. I realised it that these pills need you to rest but you cannot do that. You cannot sleep flat because all those things will be waiting for you. Here in (name of area withheld for anonymity) we get water at midnight. If the water sounds like phaaaaaa, (indicating the sound of water from a running tap) you are already up. That flat (sleeping flat) you can no longer have. Now you are working while the pills are also working, you see.* (Grandma Tamar)

Despite many success stories, the research participants acknowledge that their experiences of growing old with HIV involve a number of complications and challenges. Theory suggests that part of constructing reality involves acknowledging or being conscious of the complications and challenges within the lifeworld (see section 1.3.2 (pg.30). Grandma Kate who used to be a cross-border trader thinks that HIV and age are working together to cause the problem with regard to her legs that she is experiencing:

*As a person, I, I sell stuff or go to Mozambique. Up until I said eee. I cannot do this anymore. I cannot walk long distances anymore. I can’t do that. I get tired and feel very weak. Haa, my legs are now a problem. I am now going there only once a month. It is now difficult. I cannot go to Mozambique to sell stuff everyday like I used to do. I am now just going there to buy some stuff for us to use at home. So it’s no longer giving me profit like it used to do when I could go there every day.* (Grandma Kate)

Some of the research participants report that they seek help from others when facing challenges, as Grandma Mecky points out:
So at times people from the community come to help. Even people from church. If I say I am not feeling well, they come to help. ... Or even my children, they help me a lot. And you see that things go well if people are doing that. (Grandma Mecky)

However, Grandma Vicky who also used to be a cross-border trader says she does not feel the effects of HIV on her. She believes that it is her age that has caused her to retreat from the buying and selling business:

No, no HIV is not doing anything. [It is] age ... I [can] do anything. All those things that a person does every day – in the fields, garden, cleaning the house, anything. There is nothing that I cannot do. God keeps me strong, even at this age, I can cultivate the fields and do anything. Ha-a, the [HI] virus has no problem because right now even where it itches I don’t have. Age is the only problem that makes me say: aah, that this I cannot do any more. Some of the work that I used to do, big jobs, I have left them. I saw that I cannot carry those heavy bags anymore to go and sell in South Africa. I cannot do it anymore. I am old now. It was possible before then. But I cannot say it’s HIV. I may lie, my body is very, very strong. (Grandma Vicky)

There are some research participants who point out that they are managing on their own without any problems. Grandma Jessy is one such person who says that she can do anything without anybody’s help. Here is what she has to say:

Myself there is nothing. No work is heavy for me. I sew stuff and nothing is difficult for me. I actually saw that the medicine (ARVs) helped me. When I started taking the medicine (ARVS), I started to feel well; to actually feel new. So there is nothing that is a problem to me. Even sweeping in my house, I do it myself. ... I can wash my own clothes, clean the house, [I can] do anything. At times I don’t even like it when someone does it for me. I want to do it myself, yes. (Grandma Jessy)

There is another challenge relating to healthcare service that came up during the conversations which has an effect on the proper management of HIV in older people. Although a greater number of the participants confirm that they face no major problems at the clinic where they collect their treatment, some are very anxious about the service fee that they pay:
Eer, medicines (ARVs). We take them from the clinic. We pay $2 for the [Medical record] card. At times you will not have the $2. Those are some of the problems we face. Problems that make you stressed. That, my God! Eer, if you hold your card like this you say: “$2, it’s now wanted. I am about to go back for the tablets, My God! The date is now close, My God!”

(Grandma Rose)

Grandma Kate raises another striking point regarding services at the health centre she visits. She complains about the attitudes of health workers and shows that this can be a deterrent to managing HIV and seeking medical help. Her story exposes some stigmas perpetuated by health practitioners towards patients. This is what she says about it:

Aah, this other day I went there with a headache and I started by saying: “You see, my hands are swollen, this and that. Plus I am getting tired easily”. Then he (the doctor) gave me some tablets and I left. On the next occasion he said to me: “That is what AIDS is. So what do you want me to do?” (Grandma Kate)

Some of the research participants’ views on treatment reveal the big role that family members play in upholding treatment adherence to a person who is on ART. It also proves that good familial ties uphold the wellbeing of a person who is living with HIV, as pointed out by scholars such as Patel, Ratner, Gore-Felton, Kadzirange, Woelk and Katzenstein (2011: 358) and Duracinsky, Herrmann, Berzins, Armstrong, Kohli, Le Coeur, Diouf, Fournier, Schechter and Chassany (2012: 501). Grandma Mecky’s story also touches on the importance of openly living with HIV. She is openly living with HIV and as such she is open about everything to her children, including the medication that she is on. As a result, she can send her children to collect her medication on her behalf. She also touches on reciprocity of will, which intersubjectively emanates from reciprocity of perspectives (See section 1.2.3, pg.22) when she talks about the child’s willingness to collect the medication on her behalf. Here is Grandma Mecky’s account
relating to the above discussion when I asked her if there are any problems in sending her child to collect the ARVs on her behalf:

No problem at all. But you have to see if the child is willing to go and stand in a queue for people who are known to be living with HIV. So it needs the child to be willing. (Grandma Mecky)

This willingness clearly emanates from her disclosure and the counselling that she gave her children with regard to her condition. In addition, her involvement of the children in decision-making with regard to her HIV activism work, contributes to the willingness of the children to help her wherever there is need:

So I had to explain to her on the issue and told her that: My child this is what is there (I am HIV-positive). The treatment that I take is this one”. That thing we call disclosure. ... I first sat down with my kids and I told them that there are people who requested me to have my story featured in the Manica Post (local weekly newspaper). I had been approached by the newspaper people and I said: “Let me talk to my children first”. Because a child must not hear it or see her mother on TV or in the newspaper without her knowledge. (Grandma Mecky)

Some of the research participants feel that they have had enough of HIV and just wish for a complete cure and an end to the pandemic. Although they are living positively, their sentiments demonstrate that they cannot endure the stressor forever:

What we want is only that the hospital must tell us that: “What we have given you now is everything that makes this disease (HIV) go away. ... Then this disease ends for life. Nothing else. Then I would see that I am picking up again. A fresh start. (Grandma Rose)

In short, managing one’s condition requires a high level of judgement and decision-making to work out the most appropriate and useful things that enable one to adapt and adjust to living with HIV into old age. The research participants have demonstrated that they live a normal life through self-control and self-management. They also create and recreate meanings
accordingly and thus maintain social order as they age with a condition that is often stigmatised in their society.

### 4.4 Life in the future

As discussed in the theory chapter, section 1.2.2 (pg.20), the pre-reflexive nature of lived experiences makes it possible for past experiences to inform the future where people assign meaning to possible unknown situations. They develop intentions and expectations of the life ahead based on past experiences because lived experiences are on-going and organised. The research participants likewise can anticipate their future based on what they have already gone through. This section therefore reports on the research participants’ hopes, wishes, fear and concerns about growing old with HIV as they picture their life in the future.

The conversations reveal that the research participants are all positive about the future. They are optimistic and living a meaningful life just like any other people even though they have HIV. The time that they have spent living with the virus, together with the recovery they had from unpleasant HIV symptoms, revived their mental and physical being. Some recount the importance of HIV research in their experiences — how they started with different drugs and how things have now become better because they can take their medication only once a day. Grandma Rose, a 50 year old widow is quite positive that an HIV cure will be available while she still lives. She says she wishes for a day when she gives a testimony on how life was before, during and after HIV. Such a mindset is consistent with Emlet, Tozay and Raveis’ (2010: 5) finding that older people with HIV maintain optimism and a positive outlook of the future. It is also evident from the research participants’ stories that they are mature enough to
know, believe and trust that an HIV cure lies in a medical break-through. The following excerpt represents their views:

_Myself, I am seeing that in future, eer. We are hearing that, eer, if God wishes, eer, that there is an injection that people say it’s available. That injection, that if you get it everything will be cleared. That it takes away the disease (HIV). I am wishing that it must be available while I am still living. In the name of Jesus it will be available while I am still living. It will be available while I still care for my family so that we can live together. I can see them living and them seeing me living. Then I would give as a testimony one day that, eer, telling a story that, eer, we once lived positive (being HIV-positive) like that at one time and we got helped with medicine (ARVs). But it is now over, you see._ (Grandma Rose)

During this study, research participants feel that they have not reached the end but have acquired the necessary ability to get the means to an end. They wish for the setbacks to be cleared so that they can regain their old selves with some looking forward to going back to their former businesses. Their wishes are represented in the following quote:

_In the case of, eer, the thing of going to South Africa, eer. I would seriously like to do that again, because that is where I am used to go. My husband left me going there. That is what makes me worried that eee. These legs; when will they get better so that I can get my passport again and go back as I used to do._ (Grandma Rose)

Others, such as Grandma Mecky, want to be more than activists and become carers for those who are affected and infected with HIV:

_My dream is to go further and do something so that I can care for the [AIDS] orphans or the [HIV-positive people in the] community._ (Grandma Mecky)

In addition, most of these women recovered from a near-death experience after taking ARVs. Having reached the rock-bottom state and looking at themselves now living without many signs or symptoms of HIV makes them feel positive about the future as they are of the opinion that
they defeated past challenges and can defeat further challenges in the future. This is reflected in many of their stories where they talked about how bad their state was before taking up ART. These experiences include hair loss (Grandmas Jessy, Mecky and Rose), a change in complexion (Grandma Rose), loss of weight (Grandmas Maybe, Mecky, Rose and Shelly) and skin irritations (Grandmas Jessy, Kate, Maybe and Mecky). Their health is restored and they now appear to be well, resulting in them being less conscious that they have HIV.

Although the women are thriving and optimistic, they reveal that there are times when they feel uncertain of what lies ahead of them. The responses to questions relating to concerns about growing old with HIV, their perspectives on HIV and ageing and the associated pessimist viewpoints, are captured by these selected responses:

*So these are the things that trouble me. That, what if I am very old; more than what I am right now. What will happen to me at that point in future? It gets you worried at times.* (Grandma Mecky)

*Aah, it is difficult. HIV is not an easy thing and it is not something to make fun of. You can see people looking fit and you think they are ok. Like myself I am strong like this and I do all my work all the days. But my goodness, there will be a time when I will not be able to do even anything. And then what will I do? It affects me. All this affects me and it troubles me that what will happen next when I get older? We can pretend that, haa, it is well with us. We are taking our treatment. But it is not easy, that is the truth. There will be a time when it is going to be heavy for us. Too much for us.* (Grandma Kate)

A different view is expressed by Grandma Vicky who earlier declares that HIV is not posing any problems in her life. She feels that her experiences and those of other people who are HIV-negative are not in any way different. This is shown in her views below:

*Haa, myself: there is nothing that makes me get worried. I am seeing myself growing old just like any other person, like everyone else. Even the ones without HIV. There is no problem.* (Grandma Vicky)
All in all, most of the research participants perceive the future as bright. The fact that most of the research participants are middle aged (average age 54) shows that they are at the peak of their lives and they are experiencing the benefits of HIV medication. They feel that they can still accomplish things irrespective of their HIV status. As people who were once knocked down by the effects of HIV and have recovered well, they believe that there are more good things to come. However, the effect of age on HIV is of concern to some because they suspect that age can worsen their condition in the future.

4.5 These women say, “It is very different for men.”

I also analyse data in an effort to discern the difference between the experiences of women and what women say about men’s experiences. It is clear from the descriptions given by the research participants that, in their minds and experience, living with HIV as a woman is different from the experiences encountered by men. The social environment, which is largely a major point of departure in sociological gender discourses, appears to be more lenient and forgiving towards men in as far as gender roles and sexual behaviour are concerned⁹. This is not to disregard that stereotypes and misconceptions regarding mainly the sexual and reproductive health of men exist in a socially constructed world. To some extent, the research participants’ narratives display perceptions and experiences that reinforce these stereotypes as they reveal how societal expectations influenced their conduct as well as their husbands’ in as far as HIV is concerned. As an interpretive study with a focus on women’s experiences, I work with what the participants say in conjunction with the relevant literature.

⁹This point is discussed in detail in the literature review chapter under gender-related experiences of women
The issue of victimisation features in the research participants’ narratives because some feel that men have the privilege of greater free-will than women. Patriarchal societies, as literature shows, can afford men a superior position in the social domain which consequently grants them greater autonomy over their own lives and the lives of women (see in this respect, section 2.9.1). Such a status quo is problematic to both men and women’s health. Women become more prone to non-volitional sexual encounters (Higgins, Hoffman & Dworkin 2010: 436) that magnify their vulnerability to HIV infection. Men’s masculine egos, on the other hand, can affect their rational thoughts regarding sexual health, treatment and good management of self and others. The following are some of the participants’ feelings towards men’s sexual behaviour:

_Living as a woman is different from that of a man. Because if men know that this woman is HIV-positive they start t-o, t-o, they do not love that person. They will neglect her. I don’t know. They are scared. But even if he is HIV-positive and he has things (symptoms) that show that it’s HIV, even if he proposes to a beautiful girl, he will get her. He will win even if he proposes to a very young girl. He will win her heart no matter what. … Because we are seeing very young girls getting married to old widowed men whose wives died. So I see as if life as a man is better than that of a woman._ (Grandma Jessy)

_I personally think that it is different. The difference is that a woman can stay without small houses (name given to extra marital affairs). You as a woman will be giving yourself limits. Men cannot do that._ (Grandma Rose)

In the face of such behaviours (multiple sexual partners), traditional Zimbabwean women usually cooperate as passive players in sexual encounters to support Shoko’s (2013: 21) remarks that women are socially expected to comply with passiveness on sexual issues. They usually do not leave their husbands for social status, which is mainly signalled by being in a successful marriage (Mugweni, Omar & Pearson 2015: 394). Hence, the traditional Zimbabwean social world becomes a breeding ground for women’s vulnerabilities to HIV infection. This can result in many people viewing women as innocent victims of HIV as
documented in these studies: (de Souza 2010: 250; Horne 2012: 139; McDonald 2012: 14). I use again Grandma Mecky’s words presented earlier on to illustrate her experiences regarding this issue:

There was nothing you could do. But you will know that when he comes, you will know that he is my husband. You will just meet (have sex) like that. We did not have an opportunity to say: “No-no-no, let us use a condom”. (Grandma Mecky)

Grandma Kate compares a man and a woman’s roles and thinks that life is different. She thinks that men worry less about the day to day routines at home and are likely to expect care from their spouses regardless of their fitness. The description confirms that women perform the role of primary care providers in the family (Muller 2005: 53) and sometimes with limited support (Poku 2005: 100). The following quote captures this view:

Aah, men, no matter how sick you are... Even when you are both sick, eer, the two of you are sick. If he says: “I have a headache”, he sleeps straightaway. You are there in the kitchen working with your headache, going round and round with your headache in the kitchen and he expects to get all his meals, all his clothes washed. He expects his food and you as a woman is responsible for seeing to it that people have enough food to eat. And yet he is only thinking of taking a blanket to cover himself with. (Grandma Kate)

In conclusion, this chapter discusses the findings from the interviews conducted with the research participants under these sub-sections: pre-diagnosis experiences, post-diagnosis experiences, adapting and adjusting to the condition, and life in the future. These themes capture the participants’ experience with HIV and ageing and their perceptions on HIV and age in a socially constructed world. The main findings are that research participants understand their condition, have accepted it, and are creating new meanings as they typify appropriate techniques to manage their condition well. Thus, they have developed some resilience and are living well despite their condition.
The research participants have managed to adapt and adjust to the reality that they are living with HIV owing to the influence of age-driven maturity and the long period that they have been living with HIV. They feel they were given a second chance in life and do not want to compromise it by engaging in risky activities like poor treatment adherence, although socio-economic factors associated with treatment are worrying for some. Furthermore, it is clear that the research participants have overcome the stigma and discriminatory actions directed at them. Instead, they are using that negativity into something positive in their lives because they take it as a motivation to maintain their wellbeing. Their good physical and mental health is instrumental in their positive outlook of the future. Lastly, these female research participants feel that their experiences of living and growing old with HIV are different from those of men, with the view that women’s experiences are more challenging.
CHAPTER 5 — CONCLUSION

Conclusions are derived from the findings of the study, which involve eight women who are in the process of growing with HIV in Manicaland, Zimbabwe. These conclusions are also presented to fulfil the research objectives that are outlined in chapter 3 (see section 3.3, pg.77). Phenomenologically, the conclusions profile these women’s experiences in relation to how they create meaning as they make sense of growing with HIV. These experiences are broken down into different time periods as presented in the data analysis chapter. In this respect I, distinguish between these women’s experiences during the pre-diagnosis phase, the post-diagnosis phase and with regards to their adaptation and adjustment to the conditions, and life in the future. I discuss the conclusions in line with these phases in an attempt to expand our understanding and also gain knowledge about the nature of life of women who are living with HIV and growing old with it. Conclusions on the research participants’ experiences as women (gender) are also presented. Lastly, the study’s limitations, value of the research and implications for future studies are outlined.

5.1 Pre-diagnosis experiences

Pre-diagnosis experiences involve mostly, the ordinary, unquestioned and taken-for-granted issues that exist in the everyday life of a person as discussed in section 1.2.1 (pg.10). As the findings show, research participants conducted themselves in ways that conform to their society’s expectations of a married woman with less consideration of the health implications. The lived experiences of research participants during this phase comprise mostly of lack of effective courses of action against HIV and lack of knowledge about both HIV and its
existence in their lives. Before the research participants were diagnosed with HIV, they lived in suspense and with an uncertainty over the real cause of their ill-health and deaths of their family members. As a result, they could only suspect an HIV infection (see section 4.1, pg.101) or totally denied its presence in their lives (see section 4.1, pg.104). When HIV was later diagnosed, most of the research participants felt despondent and struggled to accept the HIV-positive results as shown in section 4.2. Hence, lack of knowledge and factual information about HIV impacted on the ability of research participants to take effective action against HIV.

HIV was initially treated with secrecy in the society where research participants live. As such, they lacked knowledge about the real cause of varied losses (illness and deaths) in their lives. There were no open platforms for HIV discussions both at micro and macro level and even pathologists did not openly disclose the cause of the death of their loved ones (see section 4.1, pg.108). This lack of factual knowledge on HIV often lead to disempowerment. The research participants’ actions were also guided and influenced by the society’s existing shared assumptions and perceptions towards HIV because they were personally disempowered to tackle HIV issues effectively. As results show, society dreads HIV and so did most of the research participants who struggled to accept the reality that they are living with HIV. In exploring further the lifeworld (the ordinary everyday reality) of research participants, I can conclude that the following experiences are influenced by the most common assumptions and taken for granted issues that exist in the research participants’ lifeworld.
5.1.1 Marriage secures a woman’s life

The research participants’ narratives reveal that they live in a society where married women believe that their life is secure in the hands of their husbands. This false sense of security made these women fail to recognise threats to their health arising from their husbands’ alleged risky sexual behaviours. Consequently, they admit, as married women, to living with a low perception of HIV risk and assumed that their husbands respect the same marital and fidelity values as they say they did (see section 4.2, pg.110). They allege that they had preserved their virginity until marriage, lived faithfully thereafter and never expected their husbands to be vectors of HIV. Therefore, the common assumption that a married woman’s life is secure in the hands of a man resulted in the research participants being oblivious of some health risks.

Another common assumption that exists in the society where research participants live is that HIV is acquired only if one engages in what society regards as immoral sexual behaviour. Their stories reveal that, as married women, they took things for granted that HIV is acquired by those who seek sexual pleasure with multiple partners outside marriage. This is depicted in their utterances that they are HIV-positive but had never been involved in sexual encounters with other men except their husbands (see section 4.2, pg.110). Notwithstanding the research participants’ revelations, the influence of social desirability is acknowledged in this matter. It is uncommon to reveal socially unacceptable behaviours that would label one a ‘bad’ wife — like admission that they also could have had extra marital sexual relationships.
5.1.2 HIV equals frailty

The HIV pre-diagnosis phase, where actions are mainly guided by common assumptions and perceptions in the participant’s social setting, caused them to believe that for as long as they were not feeling sick, they could not have HIV. Their society assumes that physical symptoms are accurate markers of an HIV infection, and so did the research participants. As a result, the women participants did not bother to take an HIV test. This is clearly represented in the findings where research participants did not get tested for HIV because they were feeling strong and showing no physical signs of any HIV infection (see section 4.1, pg.104). The existence of this notion that HIV exists only in those who look sickly means that most of the research participants had their HIV-positive status confirmed after their health had deteriorated drastically.

Since people in their social setting use physical markers to diagnose HIV, their relatives could not even accept that HIV and AIDS had caused the deaths of research participants’ husbands. The reality that the research participants looked strong and healthy at the time of their husbands’ deaths made it difficult to convince relatives that HIV and AIDS caused their husbands’ deaths. Consequently, the denial caused a breakdown of relationships with relatives, some of whom blamed research participants for causing the ‘unnatural’ death of their kinfolks. The participants’ in laws and other relatives expected to see a frail widow to match the cause of death — HIV and AIDS. Therefore, frailty, if used as an HIV infection marker, causes people to deny HIV and makes them reluctant to seek early intervention.
5.1.3 The more HIV is hidden, the better

The research participants’ narratives show that the reality that HIV is discredited and socially objectionable, makes it better if kept hidden. Some of the research participants did not want people to know that they have HIV for fear of being labelled as prostitutes (see section 4.2, pg.117). As a result, they took long to disclose their HIV-positive statuses. One participant whose husband tested HIV-negative was very supportive of her HIV-positive status when she disclosed it to him, but most did not openly address HIV with their husbands as they perceived it as a threat to their matrimonial relations (see section 4.1. pg.106).

Some of the research participants also assume that relationships with other people in the society would be affected if they are known to be living with HIV. They did not disclose their status as a way of maintaining both their social status and their meaningful social engagements with other people. This, at a social level, can be beneficial in preserving relationships, as other research participants note that interactions continue normally where no one knows or suspects HIV.

5.1.4 The beginning of HIV is the end of everything

Another common assumption and belief reflected in the research participants’ narratives of their lifeworld is that there is a strong relationship between HIV and ‘death’ with nothing else meaningful being expected to take place in a situation where HIV is present. Some of the participants thought that they were dying after they were diagnosed with HIV. This is revealed in, for example, Grandma Mecky’s story where she wrote a will immediately after she was told about her HIV positive status. She felt threatened by HIV to the extent that, upon diagnosis,
she saw her life ending imminently. HIV and AIDS were even called diseases of destruction, signifying the way it left homes deserted (see section 4.2, pg.111). This feeling of ‘death’ can however be overcome with the proper on-going counselling, HIV treatment and care, as evidenced by the research participants’ admission in post-diagnostic experiences discussed further on.

There is also a common belief in the participants’ contexts that if a person has HIV, she cannot be involved in any activities — whether physical or social. The narratives of the participants reveal that there is a common belief that an HIV infected person must be isolated and not allowed to participate in any events. A case where some of the research participants were excluded from catering duties and other church activities indicate a strong belief that the one infected with HIV is a less desirable person who is only destined for death. As a result, even the conjugal needs of couples are threatened, owing to this ‘death’ mentality towards HIV. Grandma Maybe’s husband stopped being intimate with her because he had received news that he was HIV-positive (see section 4.3.3, pg.139). He might have been acting out of care — not to infect her with HIV since he was not yet aware of her HIV status, but he could not picture any other way of having sexual intercourse with his wife because of his HIV-positive status at that time. Thus, the common perception that HIV is destructive impacts negatively on the research participants’ experiences for they believe that there is no ‘life’ after an HIV infection.

**5.1.5 HIV infection is determined by age**

Research participants’ stories reveal that they live in a society where HIV is mainly perceived as an infection in sexually-active younger people (see section 4.3.3, pg.141). The prevalence of this perception results in people’s doubt over an HIV infection in older people. For older
people, it brings relief that they evade some suspicions of an HIV infection as noted in some research participants’ admission that they are relieved that their age prevents people’ from noticing that they are living with a condition that evokes distaste in their society.

To conclude this sub-section, experiences in the pre-diagnosis phase are mainly guided by the commonly shared assumptions and perceptions towards HIV that exist and are entrenched in the research participants’ society. The research participants did not take effective courses of action against HIV for fear of acting against the existing common ideologies that influence relations, interactions and actions in their society. They took most things for granted because those societal assumptions and perceptions constructed their immediate experiences and lifeworld as reality.

5.2 Post-diagnosis experiences

The post-diagnosis phase is associated with experiences that relate to emotions, feelings, behavior and attitudes constituted after having received an HIV-positive diagnosis. Existential phenomenology, discussed in chapter 1, section 1.3 (pg.31) recognises that experiences (including perceptions and consciousness) are situated in particular times, places and lifeworlds. These perceptions and consciousness can evoke different emotions and feelings towards a phenomenon being experienced at a particular time. Similarly, HIV post-diagnosis experiences involve psychological aspects that come into being upon realising that one is ageing with a life-threatening condition (HIV).
5.2.1 Emotional distress

Emotional distress in the form of conditions such as hurt, shock and pain felt after being diagnosed with HIV is recorded in the findings of this study (refer to section 4.2, pg.110). The research participants’ narratives highlight the role that perceptions and consciousness play towards the changes in a person’s lifeworld following a positive HIV status. Most of the research participants did not receive well the reality of living with HIV because the general perception in their society is that HIV is destructive and undesirable (see section 4.2, pg.111). The negativity surrounding HIV therefore made the participants mindful of their condition as they try not to be identified with such a despised condition in their society. This affected them emotionally to the extent that some research participants contemplated suicide to avoid living with a despised condition.

However, intersubjectivity in the lifeworld — where everyday life is influenced by other people’s experiences and lifeworlds, enables some research participants to view HIV differently. They are aware that HIV is both a global and local epidemic and have seen other people suffering from it. As a result, they are consoled by the fact that they are not too distinct or unique in any way, nor are they the only ones living with HIV. An awareness of other people’s HIV-related experiences resulted in some of the research participants getting spared from some emotional distress and acknowledging their HIV results with less anxieties.

5.2.2 Self-pity

An analysis of the research participants’ post-diagnosis experiences reveal that HIV, if acquired unsuspectingly, results in self-pity. Most of the research participants view themselves as
victims of circumstances who ended up being victims of sexually transmitted infections despite having lived their lives according to the socially acceptable fidelity norms. Their expression of hurt is clearly demonstrated in section 4.2 (pg.110) where Grandma Kate speaks of not engaging other sexual partners besides her husband but ends up being HIV-positive. As discussed in section 5.1.1 (pg.156) these women said they preserved their virginity until they got married and remained faithful to their husbands. Getting a sexually transmitted infection like HIV therefore evoked emotions of unhappiness and self-pity because they believe that they deserve better.

5.2.3 Disclosure of HIV-positive status

The disclosure of an HIV-positive status can be involuntary. This is revealed in research participants’ narratives where they unintentionally told other people, especially relatives that they are living with HIV because culture petitions them to do so as noted in section 4.2 (pg.115). Social interactions in Zimbabwean communities speak of togetherness where no one lives like a loner. It opposes individualism as noted in Mandova and Chingombe’s (2013: 101) discussion on traditional Zimbabwe’s attributes of “Ubuntu” (see section 2.6.2, pg.55). This relates well with some of the narratives where disclosure was motivated by the anticipation of support in times of need. As a result, the research participants informed others of their medical conditions because they were aware that they might not overcome the challenges of HIV on their own. In addition, they were compelled to disclose their status owing to their awareness that HIV symptoms can be so overwhelming and not hidden completely as well as an awareness that there would be situations where they would need to prevent the onward transmission of the virus, for instance to children in their care. Besides, as widows staying within their
husbands’ extended families, they are identified with and belong to that clan. They were therefore inclined to disclose their HIV status to relatives who are culturally responsible for the widow and the orphans — in this case the research participant and her children.

Another factor that contributed to the involuntary disclosure of an HIV-positive status for some of the research participants was the pressure arising from social desirability. As it appears in some of the narratives, the participants did not want people to accuse them of immoral sexual behaviours in case they start to show symptoms of HIV infection after the death of their husbands (see section 4.2, pg.116). They, therefore, used disclosure as a way of evading blame and in the process raising the potential of making them socially-desirable.

Finally, disclosure of the news that one is living with HIV evokes emotions of relief because one would have just shared the news that is not easy to reveal. As some research participants admit, they felt that they had just unloaded a heavy burden because they were aware that being HIV-positive is not something that is socially well accepted. For this reason, most of the research participants took a long time to reveal that they are living with HIV. Upon disclosure, they felt relieved that they had finally managed to share the ‘difficult’ news as shown in section 4.2 (pg.118). Relief also comes where the recipient of the news is less judgmental of the person who has HIV. Most of the people that the research participants disclosed their HIV status to are close to them and had already suspected them of being HIV infected. So, these close people were not critical of them and disclosure occurred only as a confirmation of what they had suspected.
5.2.4 Stigma and discrimination

The research participants’ stories reveal the reality that stigma and discrimination emanate from a perceived responsibility where society supposes that a person acquires HIV through sexual self-indulgence as discussed in section 2.4, pg.42). Society blames and apportions the responsibility on the HIV-positive person, resulting in unfair treatment (enacted stigma) towards that person. People make assumptions on how HIV was acquired in order to assess the extent to which one can be blamed for being HIV-positive. Some of the research participants are not stigmatised and discriminated against because people sympathise with them (refer to section 4.2, pg.122) and perceive them as victims of circumstances. One of the research participants even consoles herself by affirming the point that it is not her fault that she is infected with HIV (section 4.3.1, pg.126), hence, it is right that she should not be stigmatised and treated unfairly.

5.2.5 Consciousness

As discussed in section 1.2.4 (pg.22), consciousness involves a person’s state of mind where thoughts and senses are directed towards things being experienced. The study’s research participants became conscious of their HIV status and were aware that they possess a condition that is detested in their society. As a result, they intentionally disguised HIV symptoms or kept their HIV status a secret (section 4.2, pg.117) before they came to terms with their HIV-positive condition. Some of the research participants covered-up skin irritations by wearing less revealing clothes (section 4.2, pg.120) and others avoided meeting people in public (section 4.2, pg.120). Their consciousness was directed at the fact that if people detest HIV, they were going to be treated as outcasts in society.
5.3 Adapting and adjusting to the condition

Adapting and adjusting to living with HIV involves experiences that relate to post-traumatic growth where some positive developments are realised after a stressful and traumatic experience (see section 2.4.2, pg.48). This positive growth include understanding, accepting and managing HIV. The research participants’ stories point towards the fact that, with time, they acquired the ability to live well with HIV as they create new meanings and gain control over their lives. In the process, they employ mechanisms to accommodate an HIV infection into their everyday experiences in an effort to limit the infection’s threats to their physical, mental and social wellbeing. The following conclusions apply with regard to the research participants’ experiences during the process of adapting and adjusting to living with HIV:

5.3.1 Understanding the condition

Understanding the realities of living with HIV into old age is demonstrated when a person shows some high levels of physical and mental competencies to (re)create social order (relationships, practices, expectations, structures and interests) that would have been disrupted by HIV. Research participants made efforts to acquire constructive ways of living with HIV by seeking recommended treatment and exposing themselves to HIV-affiliated platforms, like joining support groups where they gain substantial information about, and support with regard to HIV. They came to understand that HIV is manageable and can be like any other chronic medical condition (section 4.3.1, pg.126). They also acquired factual information on the transmission, treatment and care of HIV that is influential in casting away myths, stereotypes, doubts, fears, anxiety and uncertainties that exist in their society. Hence, they are adjusting and adapting to their condition with an understanding that what society regards as a most
unpleasant condition is not necessarily the worst. In fact, some of the research participants appreciate HIV as they understand and view it as a blessing in disguise. The fact that HIV also opens up personal development opportunities for them (see section 4.3.1, pg.127), adds to their positive attitude.

Generally, the research participants’ understanding of their condition enables them to be more empathetic to other people who are also living with HIV. Some now offer personal testimonies and counselling because of the post-traumatic growth that enables an increased emotional connection to people who are experiencing the same challenges as themselves (see section 4.3.1, pg.125). They do not want others to go through the ‘tough times’ they endured before they understood their condition because they know that HIV is devastating if it is not curbed at an early stage. The research participants’ understanding of their condition therefore is instrumental in the adapting and adjusting process because it helps them to make sense of their experiences as they seek to live a meaningful life for themselves and with others.

5.3.3 Managing the condition

The research participants demonstrate their capability to manage their condition in their attempts at making sense of the reality of living with HIV into old age. They develop motives to restore and maintain their wellbeing and their relationships and minimise the effects of other disruptions arising from HIV. At this point, research participants’ management of HIV is not led by common societal assumptions and perceptions concerning HIV. They make rational decisions and combine the factual knowledge with the “in-order to” and “because” motives discussed in section 1.2.1 (pg.18) in an effort to live meaningfully with HIV into old age. The reality that the research participants are mature and older adults who have adopted a strong
health focus means that they can defy societal assumptions and common perceptions that are detrimental to their health in order to manage their condition effectively. It is evident in the confession of some of the research participants that they no longer carry out some of their roles as grandmothers because they increase the risk of infecting their grandchildren. Others too, no longer follow traditional practices blindly without considering how the practices affect their health (see section 4.3.3, pg.135). They have also retired from activities that are too demanding physically to accommodate the challenges of HIV and age in their everyday experiences.

To conclude this sub-section, experiences in the adapting and adjusting phase are mainly a result of personal strengths and growths in the face of a stressful HIV diagnosis. Post-traumatic growth, as it is termed, brings out a stronger self with new perspectives on life where priorities are reappraised to focus more on living better. As research participants make sense of their condition, they focus more on the positive things to live a meaningful life. They therefore, made efforts to understand, accept and manage their condition.

5.3.2 Accepting the condition

I also conclude, from research participants’ narratives, that they believe that the longer they have lived with HIV the more accepting they have become of their condition. This revelation points to the reality that accepting one’s condition is a process that takes time as described by these women who took months receiving counselling and took long to disclose their HIV status. Above all, the research participants came to the realisation that they cannot change anything about their medical condition other than their attitudes and perceptions (see section 4.3.2, pg.130). The realisation that HIV has no cure made research participants accept the reality that their condition cannot be changed and this helps them to deal constructively with life and the
negative reactions from other people as depicted in their stories. They have therefore, adapted and adjusted to their condition by framing their minds positively towards the reality of growing old with HIV.

Furthermore, the research participants’ stories indicate that the process of accepting one’s condition involves love, care and compassion. Their experiences of social networks demonstrate the need to connect with people who are tolerant and not judgmental of their condition in order for them to adapt and adjust well to the reality of living with HIV. That is why the research participants establish networks with HIV-positive people as they share the same experiences (see section 4.3.2, pg.131). Thus, acceptance of a condition takes time and is contingent with how people relate with each other.

5.4 Life in the future

The future of the research participants as they grow old with HIV seems to be filled with hopes, wishes, fears and concerns of what lies ahead. They went through the struggles of the pre-diagnosis and post-diagnosis phase and then created new meanings to regain control of their lives in the adjusting and adapting phase. As such, they can project the future with reference to their past experiences as is suggested by theory that lived experiences inform and shape each other (section 1.2.2, pg.20). Some hope that one day there will be a cure for HIV and that they will live to see it. Others have regained good health and as such see themselves reviving their previous engagements such as their cross-border trading as highlighted in section 4.4 (pg.148). Despite this positive outlook, some of the research participants feel that the combination of HIV and old age can have negative consequences on their lives. They are pessimistic that the future can become challenging because they are aware of the effects of
age and HIV on their bodies (see section 4.4, pg.149). Nevertheless, the research participants’ past experiences inform the future as they base their vision of the future from past struggles and accomplishments.

5.5 Gendered experiences

An exploration of women’s experiences brings forth an understanding of how the research participants’ life is gendered. Their narratives reveal some gender inequalities that have negative implications on the experiences of mainly married women, starting from HIV prevention, to care and support. The research participants, as women who live in a society that expects women to be less assertive in heterosexual relationships, became victims of HIV through the seemingly risky behaviours of their husbands, as was their testimony during the interviews. As findings show, some of them did not question their husbands’ infidelities even though they were fully aware of the dangers of such behaviour because their inferior social status makes them subservient. Others did not implement relevant HIV prevention measures such as condom use for fear of being labelled as prostitutes. HIV is assumed, in their society, as a ‘prostitute’s disease’, thus, they feared that they would be accused of prostituting HIV into the family (see section 4.2, pp.116&106). Some kept quiet because they felt they would not be listened to when they engage their husbands in such conversations, as is sometimes the case where one party dominates the other in a relationship (see section 4.1, pg.108).

In addition, as older women, they found it difficult to leave their spouses even when they faced the real threat of HIV infection. Findings from this study show that some of the women could not divorce their husbands because of their age (section 4.1, pg.107) and, as literature shows
they occupy a more valued social status as married than as divorced women. As a result, they became victims of HIV to preserve their social standing.

Another gender-related point that emerged during the interviews is the assumption that women, as primary carers in the family, should perform their roles no matter how unwell they might feel. The fact that they live in a society where women mainly oversee family provisions forces some of them to overwork in a bid to realise that responsibility. For example, the water shortages in the city where participants live result in them getting water supplies in the middle of the night (see section 4.3.3, pg. 143). These women are forced to wake up to fill water containers even though their HIV medication requires them to have sufficient sleep and rest. The fear of being labelled less of a mother or wife reveals the extent to which roles of women can be gendered.

In addition, the socio-economic status of the research participants as unemployed housewives or traders with unreliable income contributed to their inability to take an effective course of action to combat HIV through HIV prevention, treatment and care. Some of the research participants failed to secure HIV treatment for their family members who were dying of AIDS because they were not financially equipped to intervene (see section 4.1, pg. 107). The story of Grandma Jessy who was a stay-home mother at that time and could not afford to buy the then expensive ARVs for her husband and children, exposes how the socio-economic status of women contributes to their disempowered experiences.

In conclusion, the social status of the research participants as women is significant in showing how gender influences their experiences. The gender inequalities that exist in most heterosexual relationships in Zimbabwe often impact negatively on women’s experiences
because they offer less opportunities for women to raise their concerns over risks to their health. Women too can endanger their health as they fulfil their social roles as carers, overseers and providers of necessities in the family. Their gendered social status can also limit the possibilities of becoming economically independent as they confine themselves to their sanctioned role in society as home-makers.

5.6 Limitations of the study

Although the study gives some unique insights into understanding the experiences of older women with HIV, it has limitations. Firstly, qualitative research is subjective and relies mostly on the willingness of the participants to share what they can recall from their experiences. Gaps may occur owing to participants’ failure to fully share their personal and private experiences, perhaps partly because a particular version of reality allows them to look better in the eyes of the researcher. It is also known that some of the issues surrounding HIV can be emotionally overwhelming and might be traumatic, as a result, I was very cautious about leading the participants into such psychological states, hence my probing on sensitive issues was limited.

Secondly, bias or unfair representation is difficult to eliminate in qualitative studies where purposive and snowballing sampling are used. Since I selected research participants using snowballing, I ended up with a group of people who belong to one support group. Only one participant is from another support group. Therefore, the purposive and deliberate choice of participants, particularly via snowballing, can affect the quality of the research findings because a homogenous group emerges, which lacks varied perspectives. Nonetheless, the attitudes, worldviews, tone, expressions and the way the research participants describe their
experiences is not very different from the descriptions in the literature examining people who share common conditions and coping strategies.

5.7 Value of the research and implications for future study

The findings of this research should improve knowledge and understanding of the nature of life encountered by some Zimbabwean women who are growing old with HIV, since no other study in this context was identified in the literature review. As such, this study adds to the knowledge base on HIV and ageing with a particular focus on women’s experiences in a specific cultural and structural context. The study also highlights the often unnoticed everyday life of older women living with HIV since much focus is on women who are younger. This study is qualitative and only limited to a small group of women in one province, bigger studies involving larger cohorts are, therefore, recommended for more generalisable findings.
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174


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APPENDIX 1 — ETHICAL CLEARANCE (UFS)

Faculty of the Humanities

19-Oct-2015

Dear Mrs Chikonzco

Ethics Clearance: Growing old with HIV: Narratives of women in Manicaland, Zimbabwe
Principal Investigator: Mrs Ndahiti Chikonzco
Department: Sociology (Bloemfontein Campus)

APPLICATION APPROVED

With reference to your application for ethical clearance with the Faculty of the Humanities. I am pleased to inform you on behalf of the Research Ethics Committee of the faculty that you have been granted ethical clearance for your research.

Your ethical clearance number, to be used in all correspondence is: UFS-HSD2015/0345

This ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the ethics office to ensure we are kept up to date with your progress and any ethical implications that may arise.

Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Prof. Stephen Walker
Chairperson: Research Ethics Committee
Faculty of the Humanities
APPENDIX 2 — ETHICAL CLEARANCE (MRCZ)

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazowe Street
P. O. Box CY 573
Causeway
Harare

REF: MRCZ/B:931

Ndakaitel Chikonzo
University of Free State
Sociology Department
P.O. Box 339
Bloemfontein
South Africa

REF: GROWING OLD WITH HIV: NARRATIVES OF WOMEN IN MANICALAND, ZIMBABWE

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has reviewed and approved your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:

a) Study proposal
b) Data Collection Tool (English and Shona)
c) Informed Consent form (English and Shona)

- TYPE OF MEETING: Expedited
- EFFECTIVE APPROVAL DATE: 23 November 2015
- EXPIRATION DATE: 22 November 2016

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.

- SERIOUS ADVERSE EVENT REPORTING: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.

- MODIFICATIONS: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).

- TERMINATION OF STUDY: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.

- QUESTIONS: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You’re also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully,

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

194
APPENDIX 3 — INFORMATION SHEET

Information sheet to participate in the study entitled: Growing old with HIV: Narratives of women in Manicaland, Zimbabwe.

Dear Research Participant

My name is Ndakaitei Chikonzo. I come from Mutare, Zimbabwe but I am currently studying at the University of the Free State in South Africa. I am studying for my Master’s degree in Sociology in The Narrative Study of Lives Programme under the supervision of Prof. J.K Coetzee and Dr. A. Rau.

I am carrying out research on the everyday experiences of older women who are living with HIV. I would like to interview you on your personal experience of ageing with HIV and how society influences your experiences. I am interested in the story of your life, so be free to talk and remember that there is no right or wrong answers. I am looking forward to have interviews with you and I will try to avoid having long interviews.

The University of the Free State has given me permission and has granted me ethics clearance to carry out this research project. I intend to interview eight people who will be recruited either through organisations that work with people who are living with HIV and AIDS or referrals from people. Participants who are willing to partake will be asked to leave their names and contact number and then I will make contact with them. Participants will be in turn asked to spread the word amongst their own contacts. Again, any contacts who are willing to take part will send their names and contact number through that participant.

You should only participate in this study if you are willing to do so. Your participation must be voluntary and should only be possible if you understand what the study involves. You will be given a thank you token in the form of a grocery voucher for agreeing to participate in this project.

For the purpose of this study only, the interviews will be digitally recorded. I have a qualification in HIV/AIDS management and I am aware that issues surrounding HIV are
sensitive and can evoke discomfort. If ever you feel uncomfortable, you are free to alert me. I will discuss the matter with you and we can decide mutually whether to stop or cancel the interview. You can also ask for all your information to be withdrawn from the study at any time. If you experience any difficult emotions because of the interviews with me I will make sure that a qualified expert is contacted and able to assist you if it is necessary.

As a participant in this research project, you must be aware that I will protect you and your family in all ways possible. Firstly, your real name and those of other family members that you mention during the interviews will not appear anywhere in the report. I will use a pseudonym to protect your identities. Secondly, no other person will have access to recordings and interview transcripts except myself and my research supervisors. I will put a password, that is only known to me, on everything that I store on the computer and I will keep all recordings and hard copies under lock and key.

Please be aware that you are free to decide on the place and time that is comfortable for you to conduct the interview. Should you need more information, you are free to contact me on my cell number (Zimbabwe) 00263734230587, (South Africa) 0027799836606.

Email: chikonzo.ndakaitei@gmail.com or 2014214742@ufs4life.ac.za You can also get hold of my supervisor Prof. J.K Coetzee on 0027514012881 or Dr. Rau 0027514013750.

Thank you.

Yours sincerely

Ndakaitei Chikonzo
Dear Participant

I would like to invite you to take part in my research project: Growing old with HIV: Narratives of women in Manicaland, Zimbabwe. This study is about experiences of older women who are living with HIV in Manicaland, Zimbabwe.

I would like you to participate in this research because you are an older woman who is aged between fifty years and sixty-five and is living with HIV. The reason I am doing this study is to get a better understanding of how life is for a woman who is growing old with HIV.

I am aware that it might be difficult for you to participate in this project. I will take all steps possible to protect you from any embarrassment and or hurt. I will conduct the interviews only if you are prepared to discuss HIV issues related to your life. To lessen discomfort, I will try not to ask too sensitive questions, and it is your right not to answer anything if you don’t want to. For privacy and security purposes, I will carry-out the interview only at a place and time that is convenient to you.

As a participant in this research project, you must be aware that I will protect you and your family in all ways possible. Firstly, your real name and those of other family members that you mention during the interviews will not appear anywhere in the report. I will use a pseudonym to protect your identities. Secondly, no other person will have access to recordings and interview transcripts except me and my research supervisors. I will put a password, that is only known to me, on everything that I store on the computer and I will keep all recordings and hard copies under lock and key.
While I greatly appreciate your participation in this important study and the valuable contribution you can make, your participation is entirely voluntary and you are under no obligation to take part in this study. If you do choose to take part, or if an issue arises which makes you uncomfortable, you may at any time stop your participation with no further repercussions.

I hope you may benefit from this study by having a safe and supportive space to speak about the challenges as well as the successes in your experience of ageing with HIV. Research findings will highlight the often unnoticed everyday life of older women living with HIV to policymakers.

Where possible, the people in charge of the Narrative Study of Lives programme in which this study belongs, offer a token of appreciation to thank research participants for their time and help. You will therefore receive a small shopping voucher to thank you. If you experience any discomfort or unhappiness with the way the research is being conducted, please feel free to contact me directly or my study supervisor Professor Coetzee to discuss it. Our addresses are shown above.

Should any difficult personal issues arise during the course of this research and you feel that you need professional care, I will arrange that a qualified expert is contacted and assist you. I will seek the service of a counsellor to help you. Mr Duru or Mr Tichiwanga are willing to assist with psychological support. They can be contacted at St Werburgh's Primary School, telephone number 020 217 026. They are part of the St Werburgh's School psychology team who are actively involved in community development and are willing to offer their help free of charge.

Yours sincerely

Ndakaiti Chikonzo
Audio, Video Recording and Photography

For the purpose of this study only, which fulfils the requirements of a Master’s degree, your permission will be sought for the interviews to be digitally recorded using a voice recorder.

Only the interview will be recorded so that I obtain all the relevant and important information that need to be incorporated in the study. This is a study that seeks to understand the experiences of older women from their own understanding, perspectives and views. Hence, their interpretations (their voices and thoughts) must be captured as said so that a true version is obtained. I will listen to the tapes and record everything verbatim (exactly what you said). Documents stored on the computer will be destroyed in any way that ensures that nothing written is readable. I can play back the tape to you if you are free to do so.

Statement of Consent to be photographed, Audiotaped or Videotaped.

I understand that audio recordings will be taken during the study. (For each statement, please choose YES or NO by inserting an X in the relevant box)

- I agree to being audio recorded  
  Yes  
  No

________________________________________  ____________________________
Name of Participant (please print)  Signature  Date
Please fill in and return this page. Keep the letter above for future reference

**Study:** Growing old with HIV: Narratives of women in Manicaland, Zimbabwe

**Researcher:** Ndakaiti Chikonzo

Name and Surname: __________________________________________________________

Age: _____________

Woman, 50-65 years old, HIV-positive

(Enter inclusion criteria type here): ______________________________

0734230587 or (SA) 0799836606

Contact number: __________________________________________________________

- I hereby give free and informed consent to participate in the abovementioned research study.
- I understand what the study is about, why I am participating and what the risks and benefits are.
- I give the researcher permission to make use of the data gathered from my participation, subject to the stipulations he/she has indicated in the above letter.

Signature: _____________________________ Date: ______________________
APPENDIX 5 — INTERVIEW GUIDE

Background information in brief

- Tell me about yourself - your name, age, religion, marriage status and your family.
- Please tell me a little about your relationship with your family – children and grandchildren.

HIV – general

- Tell me your experience of living with HIV.
- What has been your experience with HIV treatment (ARVs)?
- What about complementary and alternative treatment of HIV like traditional medicines? Do you sometimes use them?

Disclosure questions

- Do you talk about HIV with your family?
- Is your HIV positive status known to anyone else? If yes, how did they become aware of it?
- How do you feel knowing that some people are aware that you are living with HIV?
- Did your interactions with others change because of your HIV status?

Stigma related questions

- What is it like to be living with HIV in this community?
- Have you experienced any form of stigma from people who are aware that you are living with HIV?

Age related questions

- How does your age influence your daily life? Describe the things you usually do from the start of the day up to the time you go to bed.
- As an older person in the family, tell me about your roles and responsibilities to your family.
- In what ways has age affected your relationships with your family, friends and the community?
- What worries you about growing old with HIV?
Culture related questions

- In Shona culture, there are beliefs and practices that are related to health. Tell me about what they mean to you in your life.

Structure related questions

- Are you able to easily get the services that you need at the clinic? Tell me about the process starting from when you leave home up to the time you receive attention at the clinic.
- What kind of support do you get from your family and other people in society?
- Do you meet and discuss with other older women who are living with HIV? – support groups