



**Health-related quality of life of people living with HIV
receiving antiretroviral therapy in North-eastern
Nigeria: A mixed methods study**

Being a thesis submitted to the School of Health and Social Care,
University of Essex, Colchester in fulfilment of the requirements for the
award of Doctor of Philosophy degree in Public Health

**By
Ismaila Adamu Saidu**

January 2017

Abstract

Since the introduction of effective antiretroviral therapy (ART), persons living with human immunodeficiency virus (PLWHA) are living longer. Life longevity among PLWHA makes quality of life (QoL) critically important for patients, providers of medical, and social services. However, this issue has not been assessed systematically in North-eastern Nigeria. The purpose of the study was to assess health-related QoL of PLWHA receiving ART in North-eastern Nigeria using a mixed method approach. The study was based on the revised Wilson and Cleary conceptual model (RWCM) which integrates both biological and psychosocial aspects of QoL. The model has been widely applied to different population in high income countries but it has never been tested in PLWHA in resource limited countries such as Nigeria. A survey relating to various domains of QoL was completed by 443 PLWHA and path analysis was used to assess the associations between QoL domains. Structural equation modelling was used to assess the fit of the RWCM to PLWHA in North-eastern Nigeria. Furthermore, 14 in-depth interviews were conducted to explore the lived experience of PLWHA and throw light upon the associations identified in the quantitative analysis. Participants with better physical and cognitive functioning and better general health had significantly better overall QoL. General health perception and characteristics of the individual and the environment explained 87.1% of the variance in overall QoL. The results showed that the data adequately fit the RWCM (CFI = 0.934; RMSEA = 0.055, 90% CI: 0.049 – 0.062, $p = 0.089$). The analysis of the qualitative data identified five themes which in part helped to explain the associations identified in the quantitative data. These include: QoL is more than being free of disease; impact of HIV on well-being; stigmatisation; coping with HIV; playing with ART. Additionally, the data examined the impact of insecurity on healthcare and QoL as during the course of the study there was presence of political insecurity in the area. The RWCM is applicable to PLWHA in North-eastern Nigeria and provides a useful framework to understand QoL in this context. Both the quantitative and qualitative data suggest that certain aspects, eg. spirituality, stigma and treatment impact have a pronounced impact on QoL of PLWHA in this area. Recommendations are made to improve psychosocial support services for HIV-infected people.

Declaration

I Ismaila Adamu Saidu hereby declare that the ideas, data analyses, results, and conclusions reported in this thesis are exclusively my own effort, except where otherwise stated and acknowledged. I also declare that this thesis is original and has not been previously submitted for any other award, except where otherwise stated and acknowledged.

Acknowledgement

I wish to express my gratitude to Almighty Allah for the entirety of this work. Each portion of it is a manifestation of Your faithfulness. My immeasurable gratitude for guidance, knowledge and watchful eyes goes to Prof Gillian Green and Dr Sheila Black for taking time out of their busy schedule to supervise this thesis. Your vision, perseverance, and brilliant input throughout this study were beyond measurable. I want to reiterate that their constant awareness and encouragement over the whole period of my study was crucial to the completion of this thesis. Their emphasis on “*building conceptual blocks*” and “*digging a little bit deeper*” and “*think in abstract terms*” all through the data analysis and write-up stages of the research advanced my critical and analytical skills. I feel they contributed to my development as a person. I am indebted to Prof David Pevalin for his scholarly advice and encouragement to pursue this study and also his critique and assistance during the data analysis and write up were inestimable. I am also greatly indebted to Ms Jan Goodall for her time to proofread this thesis which profoundly improved the composition of this thesis

My thanks also go to Prof Haruna Yusuf, Dr Baba Goni, Dr Luqman Oyeyemi, Dr Ballah Denu, Dr Stanley Maduagwu, Dr Ahmad Alhaji Mohammed, Yahaya Jibrin and Abdulrahman Jajere of the University of Maiduguri Teaching Hospital, Maiduguri, Nigeria, too many to mention, for your assistance in mobilising the participants and facilitating the organisation of the interviews. That really assisted in completing the fieldwork on schedule. Mohammed Ismail, Mustapha Abubakar and Modu Mohammed also deserve my gratitude for their support during my data collection.

My special gratitude goes to the PLWHA in North-eastern Nigeria who took part in this study despite their busy schedule consented to answer my questions and sharing insights into their private lives with me. Your cooperation was key for the success of the study.

I am also very grateful to my wife Dr Halima Garba for her endurance and patience during the time I had been away from home. I appreciate, it was hard time but I had no alternative. Sorry for that!

Special gratitude should go many people around me during the time in University of Essex, Colchester especially Santigie Kama and Dr Kabir Ibrahim, you made my study life bearable. While I cannot mention them all, I would like to acknowledge the support from all the staff of the School of Health and Human Sciences particularly Ms Melanie Witshire and Dr Ewen Speed. What a wonderful team you were! Also, my special gratitude goes to friends especially Joy Harris, Jodie Benson, Roza Khan, Roy Bhaskar and Mohammed Ahmadhi for your support and warmth friendship we all enjoyed while my stay in the UK.

I am indebted to all my colleagues particularly Dr Anthony Adoghe, Dr Laura Knight and Dr Michel Maboh for spending good time together in the office, it has been wonderful with you all. I am grateful to my family members (specifically Dr Maryam Mahmood, Mahmood Ahmadu, Murtala Adamu, Buhari Adamu and Basheer Adamu) and friends for their immense all-round support and prayers. My Heartfelt gratitude goes to Dr Victor Utti and his family for their support. Thanks for being a shoulder to cry on and listening patiently to all my complaints and sharing in the joy.

Dedication

In loving memory

Of my brother Abdul-Azeez, may his soul continue to rest in perfect peace. Wonderful memories keep you in my heart and mind.

To Dr Halima Garba

My best friend, wife and companion for her love, understanding, unconditional support and encouragement.

Definition of terms

AIDS: AIDS is a disease of the human immune system caused by the HIV following progresses of the disease that interfere with the immune system, making the individual highly susceptible to infections including opportunistic infections and some forms of cancer. The severity of the condition depends on the stage of the disease.

Antiretroviral therapy (ART) is the combination of two or more antiretroviral drugs used to slow the rate at which HIV makes copies of itself (multiplies) in the body.

CD4+ count: CD4+ (cluster of differentiation 4) is a glycoprotein located on the surface of immune cells. When HIV attacks CD4 T-lymphocytes it suppresses the immune system of the person by targeting the CD4 receptor found on lymphocytes. Lymphocytes are white blood cells that assist in fighting infections. The CD4+ count is amount of CD4+ measured in number of cells per cubic millimetre and indirectly it shows the level of HIV disease progression (Strathdee et al 1996). Possible inability of the host to fight infections is signified by low CD4+ count thus, providing a proxy assessment of state of immunity (McCance & Huether 2006).

Comorbidity (ies): Is the presence of one or more diseases in addition to a primary disease or the impact of such added diseases. It also depicts the impact of all other diseases an individual patient might have other than the primary disease of interest.

HAART: Is the combination of three or four classes of antiretroviral drugs with aim to reduce the amount of HIV and rebuilds the immune system. These classes include: entry inhibitors, CCR5 receptor antagonists, non-nucleoside reverse transcriptase inhibitors (NNRTI), protease inhibitors (PIs), integrase inhibitors, maturation inhibitors, nucleoside reverse transcriptase inhibitors (NRTI) and nucleotide reverse transcriptase inhibitors (NtRTI). This combination helps to reduce resistance by suppressing viral replication as much as possible and the approach is subject to positive and negative synergies, which limits the number of useful combinations.

However, the combination is usually at discretion of the clinician but two nucleoside-analogue RTIs and one NNRTI or protease inhibitor are commonly used.

HIV: Human immunodeficiency virus (HIV) is a communicable disease transmitted through contact with body fluid (semen, blood and blood products, vaginal secretion and breast milk) of an infected person. The causative agent HIV often spread during unsafe sex, injection using unsterile syringe and needle, share of unsterile sharp objects and blood/blood products transfusion.

HRQoL: Is an individual's perceived social, psychological and physical health over a period. The current study assessed both generic and HIV specific HRQoL.

Overall QoL: It is described as subjective well-being that explains how satisfied or happy an individual is with whole life (Ferrans et al 2005, Wilson & Cleary 1995).

PLWHA: Are persons or individuals infected with HIV with or without progression to AIDS and at the same time living with the disease.

QoL: It is individual's sense of well-being that stem from satisfaction or dissatisfaction with the aspects of life that matter most to the person (Jaiyesimi et al 2007). Also it is person's perception of their position in life in the context of value and culture constructs in which they exist in relation of their concerns, standards, anticipations and aspirations (WHO 1995).

Symptoms: Symptoms are the abnormal cognitive, emotional, or physical status experienced by a patient which are impacted by the disease or treatment (Ferrans et al 2005, Wilson & Cleary 1995). However, intensity, distress and frequency are the dimensions largely use to measure symptoms (Ferrans et al 2005).

Acronyms and Abbreviations

ADL – Activities of daily living

AIDS – Acquired immune deficiency syndrome

AID-HAQ - Acquired immune deficiency syndrome health assessment questionnaire
disability index

ART – Antiretroviral therapy

ARV - Antiretroviral

BBC – British Broadcasting Corporation

CD4+ counts – Cluster of Differentiation 4 (T4)

CFA – Confirmatory factor analysis

EFA – Exploratory factor analysis

GDP – Gross domestic product

GNI – Gross national income

HBV – Hepatitis B virus

FGM – Female genital mutilation

FMoH – Federal Ministry of Health

FMoLP – Federal Ministry of Labour and Productivity

EQ-5D – European quality of life 5 dimensions

FAHI - Functional assessment of human immunodeficiency virus infection

FSW – Female Sex Workers

HRQoL – Health-related quality of life

HAART – High active antiretroviral therapy

HAT-QOL – HIV/AIDS-targeted quality of life

HIV – Human Immunodeficiency Virus

HIV-SI – HIV symptom index

IDU – Injection drug users

HOPES - HIV overview of problems evaluation system

MSM – Men who have sex with men

MOS-HIV - Medical outcomes study HIV health survey

MOS-SF 36 - Medical outcomes study short form 36

MQOL-HIV - Multidimensional quality of life questionnaire for persons with HIV/AIDS

NACA – National Agency for the Control of AIDS

PEPFAR/APIN – President’s Emergency Plan for AIDS Relief/Aids Prevention Initiative

Nigeria

PLWHA – People Living with HIV/AIDS

PROQOL-HIV – Patient-reported outcome for quality of life-HIV

QoL – Quality of life

SEM – Structural equation modelling

UK - United Kingdom

UNICEF – United Nation Children and Educational Fund

UNDP – United Nation Development Programme

UNHCR - United Nation Human Commission for Refugee

UNFPA – United Nation Population Fund

USA – United State of America

USAID – United State Agency for International Development

NPC – National Population Commission

WHO – World Health Organisation

WHOQOL-BREF - World Health Organization quality of life brief

WHOQOL-HIV - World Health Organization quality of life human immunodeficiency virus

Table of Contents

Abstract	i
Acknowledgement.....	iii
Dedication	v
Definition of terms	vi
Acronyms and Abbreviations.....	viii
List of Appendices	xvi
Chapter one	1
Introduction	1
Introduction	1
Personal information and research motivation	1
Profile of Nigeria.....	4
Governance and economics	7
Health	7
Epidemiology of HIV in Nigeria.....	9
Public health HIV prevention and control programme in Nigeria	12
North-eastern Nigeria	14
Meaning of quality of life.....	18
Measurement of HRQoL.....	23
Quantitative measurement of QoL.....	25
Qualitative assessment of QoL	29
Wilson and Cleary conceptual model.....	30
Biological function	33
Symptoms status	33
Functional status	34
General health perception	34
Overall QoL	35
Characteristics of the individual	36
Characteristics of the environment	37
Non-medical factors.....	38
Revised Wilson and Cleary conceptual model.....	38
Chapter Two.....	43
Literature review	43
Introduction	43
Method of reviewing literature that assessed HRQoL in PLWHA	43
Inclusion and exclusion criteria	44
Search strategy.....	44
Sifting of the literature	46
Data extraction.....	48
Critique of the quantitative studies that used Wilson and Cleary conceptual model to assess HRQoL	57

Critique of the qualitative studies.....	61
Findings from the quantitative and qualitative studies.....	66
Perceptions of quality of life.....	67
Biological function	68
Symptom status.....	69
Functional status	71
General health perception	74
Relationships between characteristics of individual and other components of the model.....	75
Relationship between characteristics of environment and other components of the model	80
Findings and critique of studies from Nigeria.....	91
Conflict and HIV transmission, adherence to ARVs and QoL	95
Why is this study needed?	98
Aims and objectives	101
Chapter Three.....	103
Methodology	103
Introduction	103
Epistemology.....	103
Positivism	104
Social constructionism.....	105
Research design and method	106
Mixed method research (Quantitative -Qualitative Mix).....	106
Explanatory sequential design	108
Quantitative research design: Cross-sectional survey	109
Sequence of the research	111
Quantitative research	111
Sample size	111
Sampling procedure of the quantitative study	112
Accessibility and recruitment of the participants for the quantitative study	116
Quantitative survey instruments	117
Data Collection: The quantitative research	120
Data quality assurance mechanisms of the quantitative research.....	123
Data checking	123
Quantitative data analysis.....	123
Descriptive statistics	123
Inferential statistics.....	124
Normality tests.....	126
Data cleaning and preparation for SEM	132
Qualitative research design.....	133
Inclusion criteria of the qualitative research.....	133
Sampling procedure of the qualitative research phase	133
Accessibility and recruitment of the participants for the qualitative study	134
Data Collection: The qualitative research	135
Data management and data quality assurance of the qualitative research.....	137

Qualitative data analysis.....	139
Merging the quantitative and the qualitative findings (interpretation).....	141
Ethical considerations.....	144
The role of the researcher and development of the study.....	145
Positionality	148
Chapter Four.....	153
Results of the quantitative study	153
Introduction	153
Sample characteristics	154
Bivariate correlation analysis	158
One-way path analysis.....	161
Direct effect of biological function on symptom status.....	161
Indirect effect of biological function on functional status, general health perception and overall QoL.....	163
Direct effect of symptom status on functional status.....	164
Indirect effect of symptom status on general health perception and overall QoL.....	165
Direct effect of functional status on general health perception	165
Indirect effect of functional status on overall QoL.....	166
Direct effect of general health perception on overall QoL	167
Direct effect of characteristics of the individual on biological function, symptom status, functional status, general health perception and overall QoL	170
Direct effect of characteristics of the individual on biological function	171
Direct effect of characteristics of the individual on symptom status.....	173
Direct effect of characteristics of the individual on functional status	174
Direct effect of characteristics of the individual on general health perception	175
Direct effect of characteristics of the individual on overall QoL	176
Direct effect of characteristics of the environment on biological function	178
Direct effect of characteristics of the environment on symptom status.....	178
Direct effect of characteristics of the environment on functional status	178
Direct effect of characteristics of the environment on general health perception	179
Direct effect of characteristics of the environment on overall QoL	179
Structural equation modelling (SEM)	182
Step 1: The measurement model.....	183
Step 2: The structural model.....	191
Summary and interpretation of the quantitative findings	196
Chapter Five	205
Results of the qualitative study	205
Introduction	205
QoL is more than being free of disease	209
Impact of HIV on well-being	212
Impact of HIV on social relationships with family and friends.....	213
Impact of HIV on intimate relationship.....	215
Impact of HIV on physical functioning	217

Impact of HIV on mental well-being and cognitive functioning	218
Impact of HIV on finance and work	220
Impact of stigmatisation and disclosure on QoL	221
Actual stigma	221
Internalised stigma/self-stigma	222
Fear of being stigmatised	223
Managing stigma.....	224
Coping strategies of living with HIV infection	226
Playing with antiretroviral therapy (ART)	228
Impact of insecurity on HIV care, health and QoL	233
The relationships between the themes and QoL.....	235
Chapter Six.....	238
Discussion	238
Introduction	238
Sociodemographic characteristics and quality of life.....	238
Meaning of quality of life.....	241
Symptoms and impact on functioning	243
Impact of HIV on psychological well-being	244
Impact of HIV on intimate relationships	245
Importance of support from family and friends	246
Impact of financial difficulties on QoL.....	248
High levels of stigmatisation	249
Coping strategies of living with HIV infection	252
High levels of spirituality	252
Other coping strategies: Exercise, nutrition and ARV adherence	255
Impact of ART on QoL	256
Impact of insecurity on HIV care, health and QoL	259
Reflections on using the revised Wilson and Cleary model to assess QoL of PLWHA on ART in North Eastern Nigeria.....	260
Key findings and implications of the study	262
Strengths and limitations of the study	264
Strengths of the study	264
Limitations of the study	265
Reflexivity and reflection of bias	267
Recommendations	270
<i>HIV and social relationship</i>	270
<i>Stigmatisation</i>	271
<i>Coping strategies</i>	271
<i>Insecurity</i>	272
Conclusion.....	273
References	276

List of Tables

Table 2.1	Search terms used to identify the relevant studies.....	45
Table 2.2	Combination of Keywords to search for studies.....	45
Table 2.3	Summary of the outputs came down to a manageable number.....	49
Table 2.4	Summary of the studies that used Wilson and Cleary model to assess HRQoL.....	50
Table 2.5	Summary of the qualitative studies that explored HRQoL in HIV.....	53
Table 2.6	Summary of the studies from Nigeria that assess HRQoL in HIV	89
Table 3.1	Total number of eligible participants who have up-to-date data were engaging in the ARV clinic at the time of the study.....	114
Table 3.2	Distribution of participants by age and gender based on the calculated sample size.....	116
Table 3.3	Normality test statistics of the variables	128
Table 3.4	Summary of the variables transformed using the two-steps transformation technique	131
Table 4.1	Characteristics and clinical information of the sample	155
Table 4.2	Sample characteristics of the participants.....	157
Table 4.3	Cronbach's alpha of the PROQOL-HIV questionnaire subscales.....	158
Table 4.4	Correlations matrix among measures of variables of the model.....	160
Table 4.5	One-way path analysis of the direct effect and indirect effect between the five endogenous components of the revised Wilson and Cleary model model.....	169
Table 4.6	One-way path analysis of the direct effect of characteristics of the individual and the environment on biological function, symptom status, functional status, general health perception and overall QoL.....	181
Table 4.7	Model modification summary of the CFA result of the final 7-factor measurement	186
Table 4.8	Model modification summary of the CFA of the final 7-factor structural model of the revised Wilson and Cleary conceptual model..	194
Table 5.1	Sample characteristic description of the qualitative participants.....	207

List of Figures

Figure 1.1	Political Map of Nigeria	5
Figure 1.2	Map of North-eastern Nigeria	15
Figure 1.3	Wilson and Cleary Model.....	31
Figure 1.4	The revised Wilson and Cleary model.....	39
Figure 2.1	Flowchart showing sifting strategy.....	47
Figure 3.1	Sketch of Explanatory Sequential Mixed Method Research Design....	109
Figure 3.2	Operationalisation of the revised Wilson and Cleary model and PROQOL-HIV instrument was operationalized.....	122
Figure 3.3	Flowchart of the sampling procedure of qualitative participants.....	134
Figure 3.4	Interpretation phases of mixed data analysis	142
Figure 4.1	Direction of the path analysis as depicted by revised Wilson and Cleary model.....	161
Figure 4.2	Direct effect of biological function on symptom status and the indirect effect of biological function and functional status, general health perception and overall QoL.....	162
Figure 4.3	Direct effect of symptom status on functional status and the indirect effect of symptom status on general health perception and overall QoL.....	164
Figure 4.4	Direct effect of functional status on general health perception and the indirect effect of functional status on overall QoL	166
Figure 4.5	Direct effect of general health perception on overall QoL.....	167
Figure 4.6	Direct effect of the characteristics of the individual and the environment on biological function, symptom status, functional status, general health perception and overall QoL	170
Figure 4.7	Measurement model of the seven latent variables of the revised Wilson and Cleary model with finally seven indicators and fifteen observed variables and post-hoc modifications	185
Figure 4.8	The final CFA result of the final 7-factor structural model of the revised Wilson and Cleary conceptual model.....	193
Figure 5.1	Flowchart showing the summary how the themes were generated	209
Figure 5.2	Diagrammatic illustration of the relationships between the emerged themes.....	236

List of Appendices

Appendix I	Combination of keyword used to search for literature.....	303
Appendix IIA	University of Essex Ethical approval letter	305
Appendix IIB	University of Maiduguri Teaching Hospital Ethical approval letter.....	306
Appendix III	Participant's information sheet for the quantitative research.....	307
Appendix IV	Consent form for the quantitative research	308
Appendix V	Sociodemographic data form.....	309
Appendix VI	Biological function and clinical information data form.....	310
Appendix VIIA	PROQOL-HIV quality of life HIV questionnaire.....	311
Appendix VIIB	Hausa version of PROQOL-HIV quality of questionnaire.....	314
Appendix VIIIA	Interpersonal support evaluation list short form 16.....	316
Appendix VIIIB	Hausa version of Interpersonal support evaluation list SF-16.....	317
Appendix IX	Output of the squared root and log ₁₀ transformation.....	318
Appendix X	Factor items loading and CFA of the PROQOL-HIV subscales	320
Appendix XI	Draft of the interview questions for the qualitative research.....	322
Appendix XI	Participant's information sheet for the qualitative research.....	323
Appendix XII	Consent form for the qualitative research.....	324
Appendix XIII	Summary of the emerged themes during the stages of the qualitative framework data analysis.....	325

Chapter one

Introduction

Introduction

This study was conducted to assess HRQoL among PLWHA receiving ART in North-eastern Nigeria. Chapter one provides brief personal information and research motivation. It gives a short profile of Nigeria (governance, economy and health), epidemiology of HIV in Nigeria and public health HIV prevention and control programme in Nigeria. Further, a brief profile of North-eastern Nigeria and the study setting were discussed in this chapter. Chapter one also includes a critical discussion about the meaning and concept of HRQoL as well as different methods of assessing HRQoL.

Personal information and research motivation

I am a Nigerian. Before coming to the UK to study, I lived and worked at a tertiary hospital in Maiduguri, North-eastern Nigeria. Coming from a clinical background and practice, I was privileged to work with PLWHA in Nigeria, and I noticed that the services rendered to PLWHA mostly focus on the provision of medical treatment, specifically ART, aiming to improve the compromised immune system. HIV infection is a disease that does not only have a biological impact; it also impacts on social and psychological dimensions of health and well-being. During my experience working with PLWHA, I observed that despite commencement on ART some groups still presented with deteriorating QoL, which appeared to link to social and psychological factors. In the light of this, several works of literature (Duracinsky et al 2012a, Adedimeji et al 2010, Garvie et al 2009) support this observation. Since HIV infection affects many aspects of the life of the infected persons, arguably that provision of ARVs alone without other adjunct services may not be sufficient to improve QoL of PLWHA. Since HIV infection affects many aspects of the life of the infected persons,

arguably that provision of ARVs alone without other adjunct services may not be sufficient to improve QoL of PLWHA. One scenario among others that struck me was that there was a time I was consulting a patient living HIV who had been my patient for a long time. On that day he visited the clinic I noticed he was not as cheerful as he used to be and looked worried. I asked him if anything was troubling him. This patient said to me: *“Oga [Sir] ...I heard the news that we are not going to be getting our medicine [ARVs] for free again. Because I don’t know how life will be without this medicine...who can afford to buy this medicine for the rest of their lives?”* And I said to this patient that to the best of my knowledge this was not the case.

In 2002, HIV Prevention and Control Programme was introduced in Nigeria; it received funding from the USA under the programme called PEPFAR to: 1) provide free ARVs to all eligible persons; 2) exempt all HIV-related medical bill of all PLWHA; 3) provide social support to PLWHA; 4) provide financial supports in the form of food and transport vouchers etc to the poorest PLWHA. However, when the USA government under President Barrack Obama¹ reduced this counter funding by nearly half and since then there is little or no effort by the Nigerian government to continue with other aspects of the HIV care programme apart from the provision of the free ART (Odittah 2015). Considering the prevailing poverty in Nigeria, which is a considerable challenge for PLWHA in the country. Access to free ART in developing countries has had a profound impact on the QoL of PLWHA (Mutabazi-Mwesigire et al 2014, Geurtsen et al 2005, Adedimeji et al 2010). Some PLWHA in developing countries see access to ART as one of their hope for survival and to cope with the HIV infection (Monjok et al 2010). This insight prompted me to conduct a study on the impact of HIV infection in PLWHA receiving ART.

¹ The reduction of the counter funding of HIV programme in Nigeria happened during the second term tenure of President Barrack Obama. Among other reasons by the USA government for cutting down funding was the global recession of 2008. It was said that Nigeria, as one of the largest economies in Africa, should start to learn how to provide HIV care to its citizens.

In HIV infected persons the micro-organism progressively attacks the immune system (specifically CD4+ count), and the virus replicates (Soghoian et al 2012, Porichis & Kaufmann 2011, Douek et al 2002). This process renders the infected persons susceptible to several opportunistic diseases and poor health status (Balderson et al 2012) which subsequently impact on the well-being (Folasire et al 2012, Henderson et al 2012, Deribew et al 2009).

HIV infection does not only have a biological impact, but it also impacts on social, psychological as well as the physical dimension of health and well-being (Herrmann et al 2013, Folasire et al 2012, Phaladze et al 2005). Debatably, Nigerian HIV programme did not take QoL into account despite efforts by the Nigerian government to improve QoL of all her citizens. An overarching goal of Health Promotion Policy 2005 in Nigeria is to promote QoL of individuals of all ages and increase life expectancy (FMoH 2005). Therefore, identifying what aspects of individual's HRQoL are affected while living with a chronic disease such as HIV is a key challenge for health care providers and researchers (Folasire et al 2012, Garvie et al 2009, Stangl et al 2007, Mrus et al 2006). Because the provision of ARV drugs alone without other adjunct services may not be sufficient to improve QoL of PLWHA. Furthermore, it is essential to continually identify factors that influence HRQoL of this vulnerable population including issues that matter to them most. The identified factors will help to develop more robust and updated interventions that have the potential to improve HRQoL in PLWHA.

PLWHA in Nigeria now experience the same life expectancy as the general population. However, challenges surrounding lifetime treatment remain. PLWHA in Nigeria faces some complex difficulties in adapting to their condition. Many PLWHA experiences substantial life disruption such as emotional distress following diagnosis. These factors usually make it

difficult for the transition to a healthy life after being diagnosed and initiating ART (Adedimeji et al 2010). Despite the campaigns by National Agency for the Control of AIDS (NACA) to inform the population about HIV transmission, some people in Nigeria mistakenly believe that HIV transmission is through casual contact, or they make erroneous assumptions and judgments about people with HIV (Folarise et al 2012). Such misconceptions and judgments can make nurturing social relationships difficult for PLWHA. Such negative societal and socio-cultural beliefs about HIV can be debilitating for PLWHAs and incites a high level of psychological distress (Duracinsky et al 2012a). Additionally, some PLWHA in Nigeria reports difficulty in coping with living with HIV because of the prevailing social and economic challenges (Adedimeji et al 2010).

Profile of Nigeria

Nigeria locates in the West African region, between latitudes 4° and 14°N and longitude 2° and 15°E occupying a land area of 923,768 square Kilometres. Nigeria is bounded on the West by the Republic of Benin, the Republic of Niger in the North, and Cameroon and the Chad Republic in the East. Its coast lies on the Atlantic Ocean and the Gulf of Guinea in the south. In 1960, Nigeria as a sovereign Nation came into being following political independence from Britain. Approximately, the population of Nigeria is 184 million (World Bank 2017).

The nation comprised of 36 states, 774 local government councils and a Federal Capital Territory (FCT-Abuja) which is the seat of power (Garbati et al 2011, FMOH 2010). The country's system of government is a three-tier of a presidential system: the Federal Government, the State Governments and the Local Governments. The states are categorised into six geo-political zones: North-west (Kaduna, Kano, Katsina, Kebbi, Jigawa, Sokoto and Zamfara); North-east (Adamawa, Bauchi, Borno, Gombe, Taraba, and Yobe); North-central (Benue, Kogi, Kwara, Nassarawa, Niger, and Plateau as well FCT-Abuja); South-South

(Akwa Ibom, Bayelsa, Cross Rivers, Delta, Edo, and Rivers); South-west (Ekiti, Lagos, Ogun, Ondo, Osun, and Oyo) and South-east (Abia, Anambra, Ebonyi, Enugu, and Imo) (FMoH 2010, NPC & ICF Macro 2008). Figure 1.1 shows the map of Nigeria.



Figure 1.1: Political map of Nigeria (Adapted from NACA 2010)

There are over 250 ethnic tribes in Nigeria with each having their language. Amongst these tribes, Yoruba, Hausa and Igbo are the most widely spoken languages, spoken by over 40% of the population and English language is the official language of communication (NPC & ICF Macro 2008). There are two types of English language spoken in Nigeria that is, grammatical English and Pidgin (basic or broken) English. Better-educated person mostly speaks the grammatical language while the less educated persons mostly speak Pidgin English. The use

of language in communication in Nigeria is complicated. In Nigeria, Yoruba is the universal language of communication in the South-west. Hausa is the universal language of communication in the North and Igbo is the universal language in South-eastern Nigeria. Only the older generation currently other local languages such as Ijaw, Efik, Nupe, Marghi, Fulani, Ibi-bio etc. For example, in northern Nigeria; the use of grammatical English, Pidgin English or Hausa to communicate depends on whom the person is talking with (that is, how well educated the person is) and the context in which the interaction takes place. Hausa and Pidgin English are *lingua franca*² in North-eastern Nigeria. Of persons aged 15 years and above, the literacy is about 70% (male: 76%; female: 61%). In Nigeria, almost 51% of the people reside in the rural area, and 49% are in the urban area (NPC & ICF Macro 2008).

In Nigeria, Islam, Traditional (idol worship) and Christianity are the three main religions, of which 10% the population practice Traditional, 40% are Christians, and 50% are Muslims. The religious beliefs differ by regional and ethnic affiliations. The Yoruba are a combination of Christians and Muslims, the Hausa and Fulani are mainly Muslims, and the Igbo are mostly Christians (NPC & ICF Micro 2008). Religion and ethnicity engulf most aspect of the country's profile including politics, economy and the laws. For instance, Nigeria has four different legal systems: 'English Law' and 'Common Law', derived from Colonization by Britain and post-colonial independence respectively. 'Sharia Law' derived from Islam and used in the predominantly Muslim, northern regions of the Hausa-Fulani and; the 'Customary Law' derived from indigenous traditional norms and practices and mainly used in the southern region' (NPC & ICF Micro 2008).

² Also known as common language. It is a language or dialect systematically used to make communication possible between persons who do not share a native language, particularly when it is third language that is distinct from both native languages.

Governance and economics

Nigeria is a federal republic modelled after the US, with executive power resting on the president. The other two arms of government are the legislature (Senate and House of Representative) and the judiciary. Nigeria was under the military rule for nearly 30 years, however, since 1999 the country has been under a democratic rule to date. Nigeria has abundant natural and human resources, and it is currently the 6th largest exporter of crude oil in the world. Despite this wealth of resources, the majority (approximately 70%) of her population are poor; living on less than US \$1 per day (Oshewolo 2010, UNDP 2009). A report shows that the percentage of the core poor rose from 6.2% percent in 1980 to 29.3% and later dropped to 22.0% in 2004 (UNDP 2009).

However, the 2011 Human Development Report ranked Nigeria 156th out of 187 countries with GDP of US\$ 20,01 per capita, GNI of US\$ 2069 per capita, income index score of 0.434 and HDI value of 0.459 (UNDP 2011). However, between 1980 and 2011 the HDI of sub-Saharan Africa as a region increased from 0.365 to 0.459, putting Nigeria below the regional average, although, the HDI value increased remarkably from 0.429 in 2005 to 0.459 in 2011 (an average of 7% increase) (UNDP 2011).

Health

There is disproportionate healthcare expenditure in Nigeria, in which only 1.7% of GDP (approximately US\$50 per capita) is spent annually from public resources on health (UNDP 2009). The country's healthcare delivery is comprised of primary care, secondary care and tertiary care (Bangdiwala et al 2010, FMOH 2010). As at 2007, there are estimated 35 doctors and 86 nurses per 100 000 population (Bangdiwala et al 2010), and less than 40% of deliveries are attended by a skilled healthcare professional (UNDP 2009). Nigeria is the most prominent Black Country in the world with an estimated yearly population growth of 3.2%, total fertility rate of 5.7 children/woman and the crude birth of 126/1000 population (Federal

Ministry of Health (FMoH) 2010). At age 18 almost 30% of women have given birth (UNFPA 2010).

Nigeria operates a federal system. The way the health system operates is that the FMoH develops the national health policy or strategy for the whole nation. The States get funding from the federation account and decide on how to prioritise the allocation of the resources for the implementation of the health policies developed by the federal government. Challenges such as corruption and government bureaucracy make it difficult for the government to prioritise its spending on issues that will impact positively to improve the health and well-being of the people. Also, there is a lack of sufficient monitoring and evaluation on how both the federal and state government utilises these resources. For instance, research to identify local health and social problems do not get fund. Lack of funding to conduct research results in many researchers using their own limited personal funds for research which in most cases leads to research that is underfunded and lacks rigour.

Infectious diseases such as HIV/AIDS, tuberculosis and malaria afflict the lives of the people and remain endemic in Nigeria (UNDP 2009, FMoH 2005). The country has a prevalence of general acute malnutrition estimates between 6.4% and 13.1% in 2011 (UNICEF 2012). Access to safe drinking water and essential drugs is above average (67%) (Oshewolo S 2010, UNDP 2009). According to recent reports, the country's infant and under-five mortality rates are approximately 88/1000 and 143/1000 live birth of respectively in 2010 (Ekure et al 2013, Maduforo et al 2013, UNICEF 2010, 2012). Moreover, the maternal mortality rate is 704/100,000 live births (Chama et al 2010, UNFPA, 2010, Mairiga & Saleh 2009). The country's annual crude death rate is nearly 14 deaths/1000 population, and life expectancy at birth is 51 years in 2010 (UNICEF 2010, 2012). In 2010, Nigeria achieved a considerable reduction in infant and under-five mortality by 30.2% and 32.9% respectively (Ekure et al

2013, Maduforo et al 2013) including 9.8% increase in life expectancy in comparison to 1990 figures (UNICEF 2012, 2010, FMoH 2010).

Epidemiology of HIV in Nigeria

The scourge of HIV/AIDS is a public health issue worldwide (Abu-Saeed & Abu-Saeed 2013, Amoran 2012). In 2015, approximately 36.7 million people were living with HIV and nearly 2.3 million newly infected persons globally with the vast majority of this number living in low- and middle- income countries (UNAIDS 2016). In the same year, nearly 1.1 million people died of HIV/AIDS-related diseases (UNAIDS 2016). Sub-Saharan Africa accounts for 69% of global PLWHA with almost 1 in every 20 adults living with HIV (WHO 2013). In the region, there were about 1.6 million new cases of HIV infection in 2012. Nigeria is the second after South Africa with the highest burden of HIV in sub-Saharan Africa (Folasire et al 2012).

The prevalence of HIV/AIDS is generalised in Nigeria (WHO 2011b), it spreads through the social network in all social classes, profession, age group, region, states, towns and villages and 80% of the disease is transmitted heterosexually (FMoH 2011, NACA 2011). The first HIV/AIDS case in Nigeria was reported in 1986 in Lagos from a young female sex worker aged 13 years from one of the West African countries, the spread of the disease has increased significantly (NACA 2010). In 2015, there were estimated 3.5 million PLWHA in Nigeria (UNAIDS 2016), this figure translates nearly to 12% of HIV prevalence in sub-Saharan Africa.

In 2015, the prevalence rate of HIV in Nigeria was 3.1% among persons aged 15-49 years and female constituting 58% of the infection in Nigeria (NACA 2015). Among the critical high-risk population, females who have sex women (FSW), men who have sex men (MSM) and injection drug users (IDU) accounts for 24%, 17% and 4% of HIV prevalence respectively in Nigeria (NACA 2010, 2011). Other high-risk populations are often under-reported including

long-distance truck drivers and female food vendors (they are usually called “Hajiya mai towo-towo or magajiya”- [food vendor or mistress respectively])³. This under-reporting may be because of lack of rigour in the way research is conducted in Nigeria. There is a dearth of academic literature about many social and health issues in the country.

The drivers of HIV in Nigeria are related to sociodemographic changes due to labour and migration (UNICEF 2010, UNAIDS 2008, FMoH 2006) and poverty (Garbati et al 2011, Enwereji 2008, Folayan 2004). Other factors include general lack of perceived personal risk (for example, reduced condom use during casual sex) and high illiteracy (FMoH 2011). According to a national survey, 25% of young Nigerians by age 15 years had initiated sex and half of them by age 18 years have had sex (NPC and ICF Macro 2008). Given the large proportion of these youths (44% of total national population), low condom usage may be among one of the factors to have contributed to the high prevalence of HIV among the youth in Nigeria (only about 32% and 50% of young girls and boys respectively use condom during casual sex). Also, religious and cultural practices of polygamy place an essential role in influencing the prevalence of HIV in women in Nigeria. Poverty (social deprivation has led some to engage in commercial sex work) could have attributed to the high prevalence of HIV among women.

According to World Bank, about 70% of Nigerian are living in poverty (World Bank 2017). Others include lack of access to health information and harmful traditional practices such as female genital mutilation (UNICEF 2010). A systematic review found that prevalence rate of FGM is 41% among adult women in Nigeria (Okeke et al 2012). Okeke and colleagues note

³ The way this group of population contract HIV is that all motor ways have Service Station at least every 50 miles. Some of the drivers have mistresses in all the Service Station along their routes so that anywhere they pull over for a rest or for night they will take that advantage to socialise with their mistresses. Most time these mistresses have many sex partners and most of them are also food vendors. Prostitution is not illegal in Nigeria. However, the social stigma attached to prostitution is the reason why these mistresses use a food selling business to downplay their sex work. Majority of these female food vendors use the day time to sell food while in the night they engage into prostitution.

that South-west region (56.9 %) has the highest prevalence and it is practice on a much smaller scale in the north (approximately 4%). The findings also showed that both Muslims and Christians practice FGM in Nigeria however, it is more widely spread in Christian predominated parts (Okeke et al 2012).

In Nigeria, nearly 180,000 HIV-related deaths occurred in 2015 (NACA 2016). These deaths have reduced by nearly 20% compared with the figures (310000) in 2003 (UNAIDS 2004). This reduction in HIV-associated mortality may be attributed to increased access to ART in Nigeria because as at 2015, there are 445 HIV centres across Nigeria compared to 20 in 2002 (NACA 2015).

The prevalence rate of HIV in Nigeria rose from 1.8% in 1991 to peak at 5.1% in 2001 (NACA 2011, 2010) although it has been declining and now steady at 4.1% since 2010 (Folasire et al 2012, FMoH 2010, NACA 2010). The decline in the prevalence of HIV was as a result of the establishment of HIV/AIDS control programme called NACA in Nigeria. This body is responsible for providing awareness on risk behaviours of contracting HIV. These risk behaviours include casual unprotected sex, use of unsterile sharp objects, receiving unscreened blood and blood products etc. NACA used print media such as billboards, newspapers including television and radio to promote awareness about HIV transmission and prevention. Further, because 80% HIV transmission in Nigeria is through heterosexual sex, NACA also used the ABC acronyms that are, Abstinence from casual sex; Be faithful to your partner, and use Condom to control the HIV transmission. Programmes such as prevention of mother-to-child transmission (PMTCT, also known as prevention of vertical transmission), which is interventions to prevent transmission of HIV from an HIV-positive mother to her infant during pregnancy, labour, delivery, or breastfeeding has also influenced the reduction of HIV prevalence in Nigeria (NACA 2010). The advocacy of voluntary pre-marital HIV test and counselling by religious leaders before marriage might have also contributed to the

decline of HIV prevalence rate in Nigeria. This practice is widely accepted by many Nigerians because people in Nigeria take what their Imams or Pastors tell them more seriously than advice from health care providers or health educators (Oturu 2011).

Public health HIV prevention and control programme in Nigeria

NACA is the HIV prevention and control programme in Nigeria inaugurated in 2000 to serve as the highest body authorised to coordinate the national response to HIV scourge. The Federal Government of Nigeria (FGN) mandates NACA to formulate guidelines, policies and advocates for mainstreaming of HIV/AIDS prevention and control into all sectors of the society (FMoH 2011, NACA 2011, 2010). NACA aims to provide quality treatment for HIV/AIDS, opportunistic infections and TB treatment for all eligible PLWHA including to reduce the incidence of HIV transmission (NACA 2011a). The objective of this agency is to ensure that by 2015 at least 80% of eligible PLWHA are receiving ART and quality care (diagnosis, prophylaxis and treatment) based on national guidelines (FMoH 2011).

The HIV prevention and control initiative in Nigeria comprised of 6 components, these include: 1) provision of free ARV regimens to all eligible PLWHA who made the national/WHO guidelines for ART initiations⁴– achievement so far is that 446 HIV care centres were established across Nigeria and nearly a million PLWHA are on ART; 2) provision of post exposure prophylaxis; 3) prevention of Mother-to-Child transmission (PMTCT) programme – 675 centres are providing PMTCT across Nigeria, nearly 50 000 HIV positive pregnant women are receiving ARVs prophylaxis, and over 20 000 infants born to HIV infected mothers are receiving ARV prophylaxis etc have been achieved; 4) HIV

⁴ 1) Start ART in all patients with HIV infection who have a CD4+ count ≤ 350 cells/mm including pregnant women irrespective of clinical symptom; 2) Start ART in all patients with WHO clinical stage 3 or 4 irrespective of CD4+ count; 3) Start ART as soon as possible in all HIV infected individuals with active tuberculosis (TB) irrespective of CD4+ count. (within 8 weeks after the start of TB treatment); 4) Start ART in all patients with HIV infection who require treatment for HBV infection irrespective of CD4+ count or WHO clinical staging; and 5) For all HIV positive pregnant women with a CD4+ count > 350 , ARV prophylaxis should be provided for the PMTCT of HIV (FMoH/WHO 2010).

counselling and testing services – nearly a million pregnant women attending antenatal care were counselled and tested for HIV and other sexual transmitted diseases; over 2 million persons aged 15 and older were counselled and tested for HIV and received their results; 5) behavioural change programme – the achievement so far is that, in all the HIV centres in the country, condoms are distributed for free, and nearly 60% of men and about 40% of women were reported to have used condom during casual sex in 2010 compared to 45% and 28% in 2005 respectively; and 6) care and support programme – no achievement was reported and the primary challenge acknowledged was lack of funding and inadequate institutional, technical and human capacity at all levels to coordinate the provision care and support services to orphans and vulnerable children (NACA 2011). These figures were recorded in 2011, and there has been no update since on the information regarding what the HIV prevention and control programme has achieved. Furthermore, most of these recorded achievements lack reference figures from a preceded year.

The FGN through FMoH also integrated HIV prevention and control initiatives into other relevant health-related interventions. For example, to strengthen HIV response initiatives in the country, the FMoH has established policies such as National Policy on Breastfeeding in 2005 (FMoH 2005) and Nigerian National Blood Policy in 2005 (FMoH 2006). In the National Policy on Breastfeeding, HIV prevention strategy is one of the components. To promote the PMTCT of HIV through appropriate and safe measures that ensure optimal infant and young child feeding, therefore, all breastfeeding mothers that are HIV positive are advised not to breastfeed, and they are given baby food formula vouchers to feed their baby (FMoH 2005). This voucher provision has helped to reduce one of the ways of mother-to-child HIV transmission (NACA 2011). National Blood Policy supervision is by a body called National Blood Transfusion Service. Its mandate is to provide all blood and blood products that are safe for transfusion (this is, are free from all forms of diseases acquire through such

routes) (FMOH 2006). Currently, there is at least one centre in each of the 744 local government areas with functional ambulances for delivery of the blood where it is needed (FMOH 2006).

Despite ARVs being freely available in all the government HIV care designated centres in Nigeria only 51% of adults have access to ARVs, as, at 2014, this figure excluded defaulters⁵ (NACA 2015). The barriers to access to HIV care include the shortage of supply of the ARV drugs at their various registered HIV care centres (Monjok et al 2010, Health System Trust ND) and adverse drug reactions (Obi 2013). Monjok et al (2010) argue that opting for alternative healing, financial (cost of transportation), lack of confidentiality; stigma and low educational status are the significant barriers to HIV care in Nigeria. Further, lack of decentralisation of HIV care facility also acts as a barrier to accessing care and adherence to ARV in Nigeria (Adedimeji et al 2010). Currently, ARV services are centralised and locate in certain accredited health facilities in the urban areas. As such, cost of accommodation, feeding, transportation and high waiting time during a clinic visit or follow up remain worrisome among PLWHA as many travel 100 miles and more for these services.

North-eastern Nigeria

Figure 1.2 shows the geographical map of North-eastern Nigeria. North-eastern geo-political zone of Nigeria comprises of six states namely: Adamawa, Bauchi, Borno, Gombe, Taraba and Yobe. North-eastern Nigeria has an estimated population of over 20 million people. The primary economic driver of the region is agriculture. However, since 2009 when the region engulfs with political conflict, North-eastern Nigeria has experienced an increase in the poverty rate along with a general decline in living standards due to political conflict in the region (The World Bank 2016).

⁵ Persons who started ART and then discontinued due to personal choice or unknown reasons.

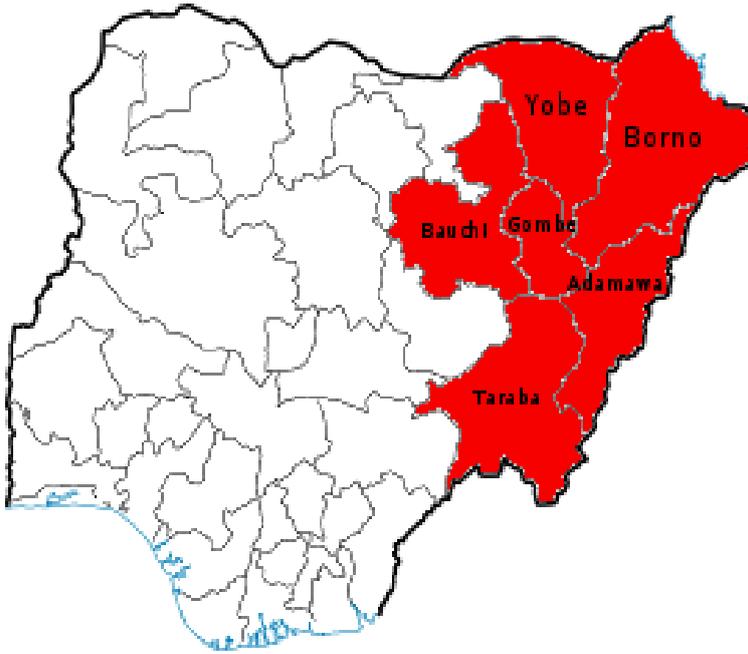


Figure 1.2: Map of North-eastern Nigeria

In 2010, the prevalence rate of HIV in most states of North-eastern Nigeria was somewhat above the national average. For instance, Adamawa state has a prevalence rate of 3.8%, Bauchi has 2.0%, Borno (5.6%), Gombe (4.2%), Taraba (5.8%) and Yobe (2.1%) (Garbati et al 2011). Reports have shown that Borno state recorded 3800 new cases of HIV infection in fifteen Internally Displaced Persons (IDPs) camps between August 2016 and March 2017 (European Affairs 2017, Vanguard Nigeria 2017) and 18101 new cases in the state as a whole (Premium Times 2017).

The high prevalence of HIV in Borno may be due to the political conflict in the region (Family Health International 2015). North-eastern Nigeria has been in political crisis since 2011. Currently, there are nearly two million people that are internally displaced with more than 80% living in IDPs camps in poverty, hunger and poor sanitation (BBC 2015, Aljazeera 2011). Another reason for high prevalence in Adamawa, Borno and Taraba may be because

the region shares some international boundaries with the Niger Republic, Republic of Chad and Republic of Cameroun and the region is very much involved with international trade with its neighbours (Garbati et al 2011). For instance, in 2012, the prevalence rate of HIV in North-western Cameroon whose border was contiguous with North-eastern Nigeria was 6.3% (Cameroon Demographic and Health Survey 2011). This figure is higher than HIV prevalence rate in Nigeria and the states in North-eastern region. Taraba state also shares an internal boundary with Benue state which has the highest HIV prevalence rate (12.7%) in Nigeria, and this may be related to across-the-border transmission of the virus (Garbati et al 2011).

Further, the low HIV prevalence rate in Yobe State may be because of the low prevalence rate of HIV in Niger republic which it borders. Since the first case of HIV in Niger in 1987, the prevalence rate has been below 1%, as at 2015, the prevalence rate is 0.5% among person aged 15 to 49 years old (no regional data available) (UNAIDS 2015). Other factors for the low prevalence rate of HIV in Yobe state may be because the state is not a commercial centre where international trade takes place with the neighbouring countries compared with Adamawa, Borno and Taraba state.

In North-eastern Nigeria there is a designated ART centre in all the state capitals that make up the region. In all the centres there is the availability of ARVs, and the provision of the ARVs is free in line with national policy on HIV prevention and control policy (FMoH 2011). As at 2014, only 33% of adults have access to ARVs in Borno State, Adamawa State had 49% and Taraba State 50% (NACA 2015). Apart from the general factors that hinder access to HIV care in Nigeria such as opting for alternative healing, financial (cost of transportation), stigma and low educational status (Monjok et al 2010) and the low coverage (which is below the national average); low access to ARV in Borno State may be attributed to the political conflict as it is the most affected state in the region (Family Health International 2015). The University of Maiduguri Teaching Hospital (UMTH) where the study was conducted

remained operational throughout the political conflict because the government deployed thousands of troops to safeguard the hospital. UMTH remained the referral centre throughout the crisis to offer medical care to all victims that got injured as a result of the political conflict; this also includes the provision of the ARVs to PLWHA who are engaged formally with the HIV care services. Other PLWHA from other parts or states in North-eastern Nigeria that are registered and receiving ARVs in their respective states and now internally displaced living in Maiduguri as a refugee was also transferred to the UMTH HIV care centre to continue receiving their ART.

Borno State has its capital in Maiduguri. The state was created in 1976 from the split of the North-eastern State. Until 1991 it contained what is now Yobe State. Borno State is bounded on the West by Yobe State, the Republic of Niger in the North, and Cameroon and the Chad Republic in the East. It is bounded in the South by Adamawa State. The State has a population of nearly six million people. Borno State consists of twenty-seven Local Government Areas, grouped into three Senatorial Districts (Borno North, South and Central). The tribes in Borno are Kanuri and Shuwa Arabs mainly found in Northern and Central Senatorial Districts and Margwi, Bura and Gwoza are in the Southern Senatorial District. The Over 70% of the population in Borno State of Nigeria are Muslims. Subsistence farming is the primary occupation of people in Borno State.

While preparing to go on fieldwork for this research, the area became increasingly politically unstable. Boko Haram, who operate in North-eastern Nigeria, became increasingly active in the area surrounding Maiduguri the town where the research was conducted (Maiangwa & Uzodike 2012). Ransack of surrounding villages, murder and kidnapping of citizens was widely reported in the international news (BBC 2015, Aljazeera 2011). The fighting affected the edge of Maiduguri, and suicide bombings were in the marketplace, places of worship, places of social function, police station, military barracks and schools (Aljazeera 2011). Boko

Haram also involves armed robbery attacks on banks, motorways and homes to get money for their finances and food. It has been estimated over ten thousand persons lost their lives due to the insurgency (BBC 2015).

The Boko Haram movement was founded in 2002. Its primary mission is opposing Western-style education (Maiangwa & Uzodike 2012). Boko Haram became increasingly radicalised which led to a violent uprising in June 2009 in Maiduguri. This violent attack was brought under control within 72 hours by the federal government of Nigeria. In 2010, Boko Haram movement resurfaced following a mass prison break. The insurgency was accompanied by increasingly sophisticated attacks, initially against soft targets, and progress in 2011 (Moore 2015, Maiangwa & Uzodike 2012). At the beginning of 2012, the federal government of Nigeria declared a state of emergency in three of the six states in North-eastern Nigeria. These include Adamawa state, Borno state and Yobe state (The Guardian 2015).

Conflict and political insecurity have been reported to affect both quality of life (Gard et al 2013, Abu-Rmeileh et al 2011) and access to HIV care (Garang et al 2009). The research thus incorporated this aspect to the study of QoL among PLWHA to reflect the politically unstable context in Nigeria.

Meaning of quality of life

QoL is a multidimensional concept encompassing all facets of life. It comprises domains of general well-being, role functioning, physical health, and concerns about the future including non-medical aspects such as environmental conditions, income, occupation, friends, and family (Gabriel & Bowling 2004). WHO defines QoL as a person's perception of their position in life in the context of value and culture constructs in which they exist in a relation of their concerns, standards, anticipations and aspirations (Bowling 2017, Rapley 2007, Bowling & Windsor 2001). The term HRQoL later emerged in the works of literature and

centred on QoL associated with health status and health care (Watkins & Connell 2004). According to Jaiyesimi et al (2007) HRQoL is not merely a description of person's health status, but precisely a personal view about health status and other aspects of life according to the participant's perception.

HRQoL is a multidimensional state of perceived health and its effect on the person's well-being (Carballo et al 2004, Murri et al 2003). Theoretically, HRQoL integrates numerous domains experienced by the patient that are influenced by health and disease (Gupta & Kant 2008). HRQoL comprises social, economic, physical, psychological, spiritual, family, cognitive and disease-related symptom domains (Andrinopoulos et al 2011, Clayson et al 2006, Garvie et al 2009). Additionally, HRQoL also describes regarding micro (subjective and individual) and macro (objective and societal) (Bowling & Windsor 2001). The former comprises person's values, experiences, perceptions of overall QoL and proxy markers of QoL such as life satisfaction, happiness and well-being whereas the later comprises the housing, environmental situations, employment, education, and income (Rapley 2007). Bowling (2009 p.7) notes that QoL is shaped by the "possession of resource necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self-actualization and satisfactory comparison between oneself and others, all of which are dependent on various experience and knowledge".

QoL is subjective, it differs from person to person, from population to population, and from country to country. QoL of a person or group is influenced by socioeconomic status, cultural difference, religious beliefs, demographic differences (for example: age, ethnicity, education, place of settlement (rural or urban)), quality of healthcare service or safety of the environment where we live and health status (being healthy or ill-health) (Rapley 2007). For example, studies have shown that people who have a higher income or better educated or belong to the ethnic majority (race or tribe) have better QoL than their counterparts (Bowling 2017, Carta et

al 2012). The reasons for this difference is that people of higher socioeconomic background tend to be better educated, have higher income, access to better health care services, access to quality housing, and live in a non-overcrowded and sanitised environment. Further, younger persons tend to have better QoL than older ones (Gabriel & Bowling 2004). Gabriel & Bowling argue that the reason for lower QoL among older persons is because they are more susceptible to age-related diseases such as hypertension, diabetes etc, and these diseases themselves can have a profound effect on QoL. In Nigeria, persons living in the rural area are likely to have lower QoL compared with those living in the urban area at least if measured objectively; this is because of the higher poverty rate, lack of equitable provision of social amenities such as hospitals, roads, clean and safe drinking water etc in the rural areas.

Understandably PLHWA are found to have lower QoL than the general population. This poor QoL is due to some factors such as the negative psychological impact of the disease on the well-being of the infected persons caused by stigma, poor social relationships, fear of death or reduced functioning (Olisah et al 2011, Murri et al 2003). Also, a reduced immune system makes PLWHA susceptible to opportunistic diseases especially for those that are not receiving treatment (Mwesigire et al 2015).

Studies have shown that persons living in a conflict area tend to have lower QoL compared with persons living in non-conflict area due to psychological trauma caused by destruction of lives and properties including living in an IDPs camps which are associated with overcrowding, poor sanitation, poverty, hunger etc (Griffith & Ford 2013, Mendelsohn et al 2012, Kiboneka et al 2008). A meta-analysis by Segerstrom & Miller (2004) reveals that people under stress have reduced immune function as a result of depletion of the CD4 cells. Therefore, PLWHA living in places of political conflict like the Borno state of Nigeria will be expected to have lower QoL than their counterparts elsewhere in the country because PLWHA in Borno are facing double challenges of living with HIV and political conflict.

However, advancement in QoL research has been impeded by the fact that the term has been used to refer to a range of different issues such as happiness, life satisfaction, well-being, psychosocial adjustment, symptoms, physical functioning and health status (Bowling 2017, Rapley 2007). As such, making a comparison of findings across studies to draw a conclusion or make application in practice is difficult (Ferrans et al 2004). In order to provide greater clarity and consistency, the term HRQoL was proposed. The term was intended to limit the focus to the influence of health, disease and treatment on QoL. Nevertheless, the differences between HRQoL and non-HRQoL cannot always be made (Jayesimi et al 2007). For example, air pollution (an environmental issue) provokes symptoms of chronic airways disorders (a health issue) which in turn impacts on QoL. Furthermore, in chronic diseases, almost all aspects of life are influenced by health status and hence, could be defined as being health related (Ferrans et al 2004).

HRQoL is defined as a relatively broad concept comprising biological, family, physical/environmental, socioeconomic, psychological/spiritual, and health/functioning aspects of an individual's life (Bowling 2009). Bowling notes that these aspects are often combined with QoL measures to create a comprehensive score that can be compared across individuals living in various cultures and value systems.

Biological aspects include molecular, cells and organ functioning that are influenced by life events such as injury, disease, treatment or health policy. The family includes those attributes related to family relationship, for example, family cohesion and integration, norms and values (Saban et al 2007).

The physical domain includes the environment where the individual lives, transport, security, traffic, accessibility to social services and health facility among others. The socioeconomic aspect involves those attributes related to socioeconomic status (income, material, education,

employment, and occupation) and sociodemographic status (age, gender, place of residence, marital status, and ethnicity) (Rapley 2007).

Psychological and spiritual domains include mental, emotional, and cognitive status for the former while religion and faith for the latter. The health/functioning domain entails general health status (presence or absence of disease) and the ability to perform a specific task (for example, physically, or socially) (Bowling 2009). The physical functioning explains how an individual or a population perform activities of daily living (dressing, eating, toileting, cleaning) while social functioning includes those characteristics such as happiness, life satisfaction, sexuality, intimacy and ability to interact with others (Rapley 2007). Thus, HRQoL can merely be defined as a value an individual assign to the duration of life as modified by social opportunity, perception, functional status and impairment that is influenced by policy, disease or health care (Jaiyesimi et al 2007).

HRQoL has been used by health care researchers especially in chronic disease research such as HIV, to assess the impact of the disease and treatment on the health status and other domains that makeup QoL (such as physical functioning, psychological and social well-being) of the infected persons (Murri et al 2003). Since the late 1990s, the introduction of an effective ART has dramatically changed the status of HIV from an acute fatal disease to a chronic illness (Mutabazi-Mwesigire et al 2014). Currently, HIV-related mortality and morbidity have reduced substantially among those infected persons who have access to ART (WHO 2013). Further, increased tolerability of the HIV medication, reduced pill burden and dosing frequency have positively impacted on HRQoL and enhanced ART compliance (Herrmann et al 2013, WHO 2013). Nevertheless, a number of PLWHA still have a lingering experience of side effects and morbidity related to the medications such as persistent immunosuppression, neuropathy and lipodystrophy which can impair QoL (Herrmann et al 2013, Duracinsky et al 2012a).

In a chronic disease such as HIV which often requires life-long and complex care and treatment, functional status and well-being are essential clinical outcomes to monitor during disease progression and for effective treatment impact (Mutabazi-Mwesigire et al 2014). Therefore, regular assessment of factors of HRQoL could help in offering a better health promotion and treatment strategies likely to optimise patients' function and HRQoL (Murri et al 2003).

Since HRQoL became an important concept in social and health care research, several approaches such as quantitative, qualitative inquiries and conceptual model have been employed to assess it, especially in HIV across different population worldwide. Therefore, it is important to briefly discuss the different approaches used to assess QoL to provide a better understanding of these approaches.

Measurement of HRQoL

HRQoL assessments have increasingly become critical in health care over the last three decades (Ferrans et al 2004), and assessment of HRQoL has increased in methodological sophistication and rigour. HRQoL is a unique and dynamically subjective perception that reflects reactions, preferences and values associated with what is essential, satisfying or the focus of attention in the life of a person (Geurtsen 2005).

Gabriel & Bowling (2004) suggest that QoL reflects sociodemographic and macro-societal effects on persons as well as their attributes and individual concerns. Thus, definition and measurement of QoL should be supported empirically by a person's assessment, while at the same time considering the broader social context (Gabriel & Bowling 2004).

Understanding of the social context is, therefore, necessary to critically situate the findings of the present study. The population of Borno (the study setting), is like other populations in

Northern Nigeria, in that its core values are entrenched in the principles of humanity and brotherhood; respect for age and constituted authority; loyalty to the family and community; co-existence and virtues of co-operation, patience and tolerance; and place a tremendous importance to greetings, truthfulness/honesty and hospitality (Hiribarren 2017). Certain health behaviours among adults such as tobacco smoking (15% and 3% among men and women respectively) and alcohol (nearly 7% and less than 1% among men and women respectively) are low among the populace due to religious beliefs and stigma associated with these behaviours (Aliyu et al 2015). These cultural traits are universal to the diverse ethnic groups and the adherents of Islam and Christianity in the Borno population in particular and generally in Northern Nigeria.

Due to the individual circumstances of HRQoL, it depends equally upon perceptions and interpretation of the individual (Rapley 2007, Geurtsen 2005, Gabriel & Bowling 2004). For example, a wealthy married woman may have entirely different HRQoL concerns compared to an unemployed and impoverished refugee from the countryside living in displaced person camps in North-eastern Nigeria. The former may be very concerned about stigma and being seen in a HIV clinic whereas the latter may be more concerned about where the next meal is coming.

HRQoL can be assessed quantitatively or qualitatively (Rapley 2007) and has also been studied by building a conceptual model such as Wilson and Cleary HRQoL model (Ferrans et al 2005, Wilson & Cleary 1995). Despite the growing interest in QoL research worldwide, there is still no consensus on whether the quantitative or qualitative method is most appropriate to assess QoL as both approaches assess different aspects. The most important consideration for any research is the aspect that they wish to investigate and the rigour of the research. However, it has been argued that the use of a conceptual model such as Wilson and Cleary HRQoL model provides a better understanding of the pattern of the impact of a

particular disease on HRQoL of a population (Sousa & Kwok 2006). Also, the Model helps to understand the relationship among the QoL domains (Ferrans et al 2005, Wilson & Cleary 1995) when compared with the conventional methods (quantitative or qualitative) of assessing HRQoL.

Quantitative measurement of QoL

A quantitative approach to assessing QoL entails the use of questionnaires to inform the outcome. There are two types of quantitative QoL measures: specific and generic QoL measures (Rapley 2007, Haywood 2006, Higginson & Carr 2001). The specific QoL measures are specific to a particular population, function or disease. For instance, the MOS-HIV Health Survey questionnaire is specific to HIV (Wu et al 1991); and the KIDSCREEN-52 is specific to children and adolescents to evaluate QoL (Ravens-Sieberer et al 2005). A disease-specific QoL measure helps to understand the details of the influence of a particular disease on the QoL in a defined population (Palfreyman 2011).

The generic QoL measures are not a disease, age or treatment specific and include various concepts of health which are essential to a general population or patients and help to compare health status between different population and between the general population and patients (Garratt et al 2002). For example, the EQ-5D (EuroQol Group 1990), the MOS SF-36 (Ware et al 2002, Ware 1997) and WHOQOL-BREF (WHOQOL Group 1998) are commonly adopted generic QoL measures both in health and diseased population. In generic QoL measures, health profile and health status of an individual or population are assessed. The generic measures have more comprehensive content however and may not capture disease-related symptoms, treatment side-effects and comorbid features that are determined by specific measures (Raley 2007). One useful feature of generic QoL measures is that they may be helpful in evaluating the impact of innovative healthcare developments where the

therapeutic effects are uncertain. For example, the EQ-5D often used to inform economic evaluations of service delivery.

When using a quantitative instrument, the true representation of a given population is always recommended through sample size estimates which help in generalising the findings. A further advantage of using a quantitative QoL measure is that confounding factors or effect modifiers can be adjusted or controlled during data analysis to get the net QoL (Rapley 2007). However, there is a bias in most of QoL tools used in quantitative approach because specific population are misrepresented during their development (Duracinsky et al 2012a, 2012b). For example, most of the existing QoL measures (both generic and disease-specific or population-specific) were developed in the USA and Europe using White populations. USA and Europe where these QoL measures were developed are high-income countries where there is availability in general of good housing, social security, food security, proper sanitation, health care services etc. All these factors influence QoL compared with middle or low-income countries where such social services are lacking. Therefore, the definition of QoL among people from these different settings (that is, between people from high income and low-income countries) may differ.

Individually, for HIV there are several HIV specific HRQoL (for example, HRQoL instruments (MQOL-HIV, AIDS-HAQ, HAT-QOL, HOPES, FAHI, MOS-HIV, and HIV-SI) instruments. However, these instruments were mainly developed in high-income countries mainly the USA often using quite specific populations, for example, English-speaking Caucasian gay men (The WHOQOL-HIV Group 2004). As such, specific populations in high-income countries may not apply to PLWHA in Nigeria. For example, a qualitative content analysis of WHOQOL-HIV in Ethiopia to explore the unique meaning of QoL among HIV receiving ARV drugs (Olsen et al 2012). Olsen and colleagues note that despite WHOQOL-HIV instrument includes many relevant domains such as social relationships, physical

functioning, and psychological well-being. In particular, the study showed that personal beliefs/spirituality/religion, environmental and social domains of the instrument were the most salient shortcomings of the tool. The themes emerged during data analysis the WHOQOL-HIV did not capture issues such as job opportunities, dietary problems, basic needs, exclusion from common resources, disease disclosure and family responsibilities. Additionally, the instrument's inclusion of drug dependence seemed of less importance in Ethiopia whereas the influence of religion was more complicated than captured in the WHOQOL-HIV. Therefore, the authors conclude that the conceptual relevance of WHOQOL-HIV is only partial in Ethiopia because of the very different population and setting used during the instrument's development.

There are similarities between Ethiopia and Nigeria. For example, the religious composition is similar as in Ethiopia about 63% of the population are Christians, nearly 34% are Muslims, and nearly 3% are practitioners of traditional faith (Abegaz 2005). Abegaz argues that most Ethiopians are well committed to their religious practice, which is similar to what is found in Nigeria. The poverty level in Ethiopia (44%) is lower compared to Nigeria where the poverty level is over 60%. Similar to Nigeria, in Ethiopia, the main health problems are communicable diseases such as tuberculosis, diarrhoeal diseases etc worsened by poor sanitation, poor housing, and malnutrition (Central Statistical Agency (CSA) 2012). In Ethiopia, the healthcare is inadequate due to lack of funding and low availability of healthcare professionals. Like Nigeria, Ethiopia is a multicultural nation which is made up of about eight different tribes, and these tribes differ in their ways of life (McDougall et al 2005). Based on the similarities discussed above thus, the study by Olsen and colleagues further justifies the claim that HIV-specific QoL measures may not be applicable in Nigeria.

Arguably, socio-cultural and semantic disparities in health belief perceived health and value systems might not be accounted for in some HIV-specific measures (Duracinsky et al 2012a,

2012b). Therefore, the applicability and transferability of these quantitative QoL tools may be limited because they may not capture the real meaning of QoL in different setting's perspective due to their rigidity.

Furthermore, many instruments were developed pre-ART and may have far less relevance to PLWHA who are taking effective ARVs (Ahonkhai et al 2012, Duracinsky et al 2012b, Clayson et al 2006). Additionally, HIV-specific QoL measures developed before the introduction of effective ART may not capture the current realities around ART such as adherence to ART, ART-related stigma, ART-related side effects and ART-related satisfaction regarding dosage, taste and pills size. Moreover, this current study was conducted to examine HRQoL of PLHWA on ART in North-eastern Nigeria.

Recently, the PROQOL-HIV questionnaire was developed post ART used quantitative and qualitative approaches in a range of high and low-income countries to construct a measure (Duracinsky et al 2012a). The countries where the participants were recruited from included Senegal, Australia, France, Brazil, USA, Cambodia, India, Thailand and China (Duracinsky et al 2012b). The main additions to PROQOL-HIV questionnaire were issues that were important to PLWHA however, not covered by any single HIV QoL questionnaire developed before the provision of effective ART (for example, MQOL-HIV, AIDS-HAQ, HAT-QOL, HOPES, FAHI, MOS-HIV, and HIV-SI) (Duracinsky et al 2012a). According to the authors, the additions of PROQOL-HIV over HIV QoL measures developed pre-effective ART include treatment issues, sleep problems, satisfaction with care, and concern for the future (Duracinsky et al 2012a). Thus, this overcomes many of the weaknesses identified in the previous HIV QoL questionnaire developed before the introduction of effective ART.

Since this study was developed and tested on a range of diverse populations and setting world-wide and was devised in the post-ART era, it was thought that it would apply to assess

the HRQoL of PLWHA receiving ART in North-eastern Nigeria. However, PROQOL-HIV may be limited for assessing the impact of political conflict on QoL of PLWHA in North-eastern Nigeria. None of the settings in which the measure was developed was undergoing such extreme conflict. Because of this limitation, an in-depth qualitative interview was used to provide more insight on the impact of political conflict on QoL of PLWHA receiving ART in North-eastern Nigeria.

Qualitative assessment of QoL

‘Exact sciences give correct answers to a certain aspect of life, but incomplete answers. It is important of course to count and measure what indeed is countable and measurable, but the most precious values in human life are aspirations which laboratory experiments cannot yet measure’ (Rapley 2007 p.103). QoL being a unique and dynamically subjective perception that reflects reactions, preferences and values associated with what is essential, satisfying or the focus of attention in the life of a person (Geurtsen 2005). Qualitative QoL assessment provides the researchers to understand respondents’ QoL in their perspective. Qualitative QoL assessment entails the use of interview (structured or semi-structured), in-depth, and focus group on assessing QoL among respondents. The open-ended character of the questions posed defines the topic under investigation but provides opportunities for both researcher and respondents to discuss the QoL topic more broadly.

The advantage of the qualitative approach is that it is flexible in which both researcher(s) and participants have a bit of control because during the process of the research some new related issues often emerge (Rapley 2007). Because QoL is a multidimensional construct, individualistic and also depends on culture, values, norms and standard of living; therefore, QoL differs from person-to-person (Chen et al 2011). Arguably, the best approach to explore QoL is to engage with the population of interest (Ming et al 2012, Ho et al 2010, Park-Wyllie et al 2007). Therefore, the qualitative approach helps to understand about QoL in a person’s

or a given population perspective and also assist in ensuring that relevant areas of concern are targeted (Testa & Lenderking 1999).

Despite the advantages of a qualitative approach in exploring QoL, it has some disadvantages. Sample size in a qualitative study is usually small and may not be a true representation of the general or focus population. A qualitative approach to assess QoL is time-consuming, for example, a meaningful, in-depth interview takes longer than completing a quantitative QoL measure.

Because of several strengths and weakness of the quantitative study and qualitative study in assessing QoL, it could be argued that the best approach to assess QoL is to mix the studies to assess QoL. Mixing the methods provides strengths that offset the weaknesses of both quantitative and qualitative research.

Wilson and Cleary conceptual model

Recently another way of describing and understanding HRQoL is by the use of conceptual models such as that produced by Wilson and Cleary (Wilson & Cleary 1995). Figure 1.3 shows the diagrammatic structure of the Wilson and Cleary model (Wilson & Cleary 1995). The model comprises five main abstract domains: biological/physiological functions/variables, symptom status, functional status, general health perception, and overall QoL (Wilson & Cleary 1995). It also incorporates individual and environmental characteristics as well as non-medical factors, such as educational status, income, employment status, housing and security that shape overall QoL.

QoL experts have argued that assessing HRQoL devoid of a conceptual model such as Wilson and Cleary model has hampered the development of a knowledge base for HRQoL study (Gorecki et al 2013, McClimans 2010, Sousa & Kwok 2006, Ferrans et al 2005, Sousa & Chen 2002, Wilson & Cleary 1995, Vallerand et al 1998). The Wilson and Cleary conceptual

model draws upon social and biomedical sciences perspectives to guide assessment of HRQoL (Bakas et al 2012, Ferrans et al 2005, Wilson & Cleary 1995).

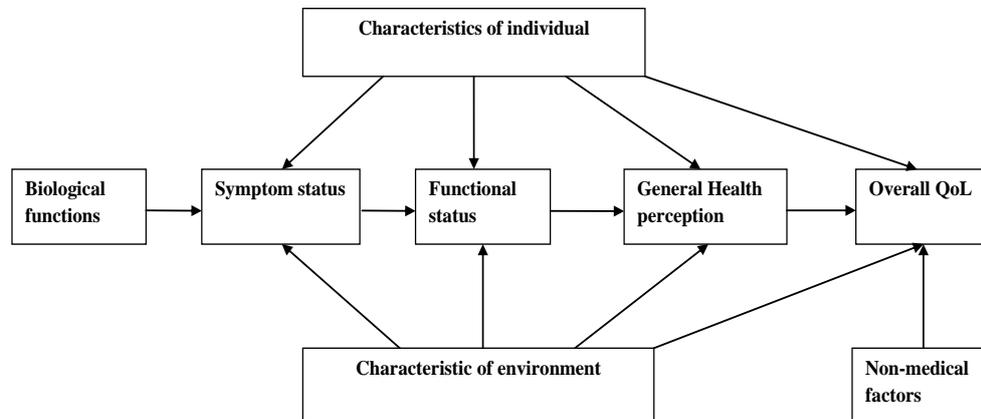


Figure 1.3 Wilson and Cleary model

The biomedical perspective of the model focuses on pathological process, physiological functions and clinical outcomes (Wilson & Cleary 1995). In case of HIV, examples of clinical outcomes include CD4+ count, viral load, comorbidity, HIV-related symptoms etc. The social science perspective considers functioning and overall well-being. Further, the social science perspective evaluates all the social factors that influence health; these factors include sociodemographic variables, income, spiritual beliefs, access to quality healthcare, emotions, security, housing etc (Ferrans et al 2005). All these are not obtained in the traditional methods of assessing QoL described above. Therefore, the incorporation of biomedical and social sciences perspectives makes the Wilson and Cleary model a potentially useful instrument to assess HRQoL for both researchers and health care providers (Sousa & Kwok 2006).

An essential aspect of this model is its theoretical approach. Atheoretical methods of assessing HRQoL, which often include multidimensional constructs, resulting in a list of variable that may impact on HRQoL but without postulations about the relationship between them (Ferrans et al 2005, Sousa & Chen 2002). Sousa & Kwok (2006) note that atheoretical methods cannot evaluate how domains are associated with one another and it is difficult to interpret the meaning or the pattern of the relationships. The basis for identifying whether QoL domains are mediated or moderated by the disease, treatment, individual, or all the three, relative to quality and cost of care outcome, is hampered when using an atheoretical method in assessing HRQoL of a population (Sousa & Kwok 2006). For example, a QoL measure may show that lack of income and lack of access to treatment both affect QoL, but it does not explain why these two domains may be related.

In contrast, the Wilson and Cleary model is structured in such a way that the nature and direction of relationship between QoL domains are specified (Bakas et al 2012). In Wilson and Cleary model there is no rigorous guideline for variable selection for the model. Rather, the model just provides a broad framework to assess HRQoL in a given population, and the researcher can decide how best to measure each element of the model. The model developers allow the absence of relationships between non-adjacent domains (that is, characteristics of the individual and environment) to be added (Wilson & Cleary 1995). The flexibility to add a new relationship between the investigated variables may also induce false assumptions when there is no theoretical basis to support that relationship. This flexibility has the added advantage of meaning that the model is more likely to apply to a wide range of settings.

The different elements of the model are briefly described below, including the most appropriate way to assess these among PLWHA in Nigeria.

Biological function

Biological function is the most fundamental determinant of health status (Wilson & Cleary 1995) and comprises the physiological processes that support life (Ferrans et al 2005). Biological function includes molecular, cells and organ functioning often assessed using physical examination, medical diagnosis and laboratory tests. For example, in case of HIV: diagnosis-related laboratory values for HIV include CD4+ count, time since HIV was diagnosed and presences of comorbidity (Henderson et al 2008, Sousa & Kwok 2006, Phaladze et al 2005) were used as proxy variables for the biological functions in this current research.

Symptoms status

As the model depicts, the symptoms encompass the abnormal cognitive, emotional, or physical status experienced by a patient as a result of the biological or physiological impact of HIV infection (Ferrans et al 2005, Wilson & Cleary 1995). The model suggests that 'symptoms' are directly influenced by biological functions, characteristics of the individual and environment. Example of an instrument used to assess symptoms status includes the global symptoms scale [for example Symptom Impact Inventory (Miller et al 2001)], and condition-specific symptoms scale [for example HIV Symptom Index (Justice 2001)] could be used to assess symptoms status in HIV (Ferrans et al 2005). Also, some HIV-specific QoL measures, for example, MOS-HIV survey, HAT-QOL etc do include a symptom domain that assesses HIV-related symptoms. These are generally assessed by the number of different symptoms the patient has or how often the patient experiences a list of symptoms associated with the disease. The severity of the symptom status of a population is usually assessed as having higher symptoms (meaning more numerous, more frequent and very acute symptoms) or having fewer symptoms (Henderson et al 2012, Wilson & Cleary 1995). For this current

research, the symptoms score and lipodystrophy score of the PROQOL-HIV instrument were used to assess the symptom status.

Functional status

This component examines the ability to carry out tasks (Wilson & Cleary 1995). Functional status includes physical, social role and psychological function (Wilson & Cleary 1995) that is often influenced by biological function and symptoms (Ferrans et al 2005). Traditionally, functional status is viewed from the angle of disability that is perceived as a loss of function as well as its impact on activities of daily living (Stineman et al 2005). Ferrans and colleagues (2005) argue that functional status should be viewed beyond disability; functional status should be viewed within a framework of functional capacity, functional performance, functional capacity utilisation and functional reserve.

Functional capacity is the individual's optimal ability to perform a specific task. Functional performance entails day-to-day activities that are carried out by an individual which are determined motivation, values and choice (Ferrans et al 2005). Functional performance may be measured using physical activity, daily memory performance or self-reported activities. Capacity utilisation refers to the day-to-day utilised percentage of functional capability. The functional reserve is the difference between capacity utilisation and functional capacity. Thus, it is vital to assess functional status as a separate variable because it may or not be related entirely to biological function or symptoms. In this study, physical and cognitive functioning score, as well as the intimate relationships score of the PROQOL-HIV questionnaire, were used to assess the functional status of the participants.

General health perception

The general health perception dimension represents all combined subjective health concepts (Wilson & Cleary 1995) that allow the individual to summarise all the preliminary concepts

including the implicit significance of each (Ferrans et al 2005). Various aspects of health in an overall assessment are synthesised in general health perceptions. Arguably, biological processes, symptoms and functional ability are the most robust and most consistent determinants of general health perceptions (Liu et al 2006a, Sousa & Kwok 2006). However, a key factor is the individual's sense of well-being (Ferrans et al 2005). General health perception is usually assessed using a single global question, representing 'an overall health rating on a Likert-type scale from poor to excellent' (Ferrans et al 2005 p.340). In this study, one single question of PROQOL-HIV that asked the respondents to rate their general health in the last two weeks was used to assess general health.

Overall QoL

The final component of the Wilson and Cleary model is the overall QoL. It is described as subjective well-being that explains how satisfied or happy an individual is with life in general (Ferrans et al 2005, Wilson & Cleary 1995). Overall QoL is thus highly subjective as satisfaction with life varies among different individuals even within a particular group. It is also highly variable among different populations and cultures. It has also been argued that a single construct does not explain subjective well-being; it comprises satisfaction with individual life domains, global judgement of life satisfaction, pleasant and unpleasant effects (Ferrans et al 2005). Because of the conceptual complexity and multidimensional nature of overall QoL, Ferrans and Powers (1992) used exploratory factor analysis and identified four factors which explained 91% of the total variance in QoL Index scores. These include family, spiritual/psychological, socioeconomic, and health/functioning.

For this research, the overall QoL was determined by the average of the total summation of scores of all the subscales of the PROQOL-HIV instrument and satisfaction with the healthcare.

Characteristics of the individual

According to the Wilson and Cleary model, the characteristics of the individual are particular depictions of the person (Wilson & Cleary 1995). The individual characteristics include demographic variables (age, gender, ethnicity, marital status and education) and psychological factors (cognitive appraisal, motivation and affective response) (Ferrans et al 2005). The effect of demography on QoL has been well demonstrated in several literatures (Akinboro et al 2014, Henderson et al 2012, Phaladze et al 2005, Murri et al 2003). Generally, younger persons, ethnic majority persons and highly educated persons have better QoL than their counterparts. Furthermore, males and married individual have better QoL than their counterparts.

Psychological factors include motivation, affective response and cognitive appraisal and are recognised as dynamic intrapersonal factors (Ferrans et al 2005). Motivation is the psychological cause of action that an individual show towards achieving the desired goal and it elicits controls and maintains certain goal-oriented behaviours (Ryan & Deci 2000). For example, adherence of ARV therapy among PLWHA. Affective responses include emotion evoked such as joy, sadness, fear and anxiety. The cognitive appraisal includes factors such as attitude, knowledge and belief toward a behaviour, disease or treatment that influences health outcome. For instance, several studies have examined the impact of anxiety, stigma, depression and cognitive function in persons infected with HIV (Chambers et al 2015, Mutabazi-Mwesigire et al 2015, Herrmann et al 2013, Henderson et al 2012, Abasiubong et al 2010). In this study, the characteristics of the individual was assessed by sociodemographic characteristics of the participants (age, gender, marital status, and educational level), social behaviour of the participants (tobacco smoking behaviour, alcohol use and illicit drug use), as well as the emotional distress, future, stigmatisation and treatment impact domain scores of the PROQOL-HIV.

Characteristics of the environment

The characteristics of the environment include either social factor (such as income, social support, beliefs and family etc) or physical factors (traffic, security, housing, sanitation [for example, exposure to environmental pollutions] etc) (Ferrans et al 2005, Eyler et al 2002, Wilson & Cleary 1995). According to Wilson & Cleary (1995), characteristics of the environment have a direct influence on symptoms status, functional status, general health perception and overall QoL. For example, studies have shown that PLWHA with higher social support (Henderson et al 2012) and better social relationships (Ming et al 2012) had better QoL. Also, political conflict or insecurity has a direct negative impact on QoL (Olupot-Olupot et al 2008). Exploring the impact of political conflict formed an integral part of this study as the impact of this on QoL is likely to be pronounced. Political conflict may mean people become internally displaced and relocate to areas where there is overcrowding, food shortages, inadequate sanitation etc (Franco et al 2006). Political conflict may also prevent victims from accessing to health care (including access to ART in case of PLWHA), all these have a negative impact on the psychological well-being and consequently QoL of the victims (Gard et al 2013, Garang et al 2009). The study area, therefore, provides an excellent platform to test the Wilson and Cleary model. Is it flexible enough to account for QoL in such an extreme setting? Moreover, if not, how can it be modified to do so? The impact of security on QoL was explored using in-depth qualitative interviews.

Characteristics of the environment were assessed by social relationship, spirituality and financial difficulty domain scores of the PROQOL-HIV and social support using interpersonal social evaluation list sixteen-items short form (ISEL-SF16).

Non-medical factors

In Wilson and Cleary model the non-medical factors include educational status, income, employment status, housing and security. The model suggests that biological/physiological variables have a direct impact on the symptoms status and symptoms status has a direct impact on the functional status. Functional status has a direct impact on the perception of general health, and the perception of general health has a direct impact on overall QoL. (Henderson et al 2012). Furthermore, the Wilson and Cleary model suggests that normal relationships exist among domains with the potential for reciprocal associations (Bakas et al 2012, Wilson & Cleary 1995). Except biological/physiological variables, the characteristics of individual and environment have a direct impact on the remaining four components of the Wilson and Cleary model. The non-medical factors have an independent impact on the overall QoL (Wilson & Cleary 1995, Noke et al 2000).

Revised Wilson and Cleary conceptual model

Figure 1.4 shows the diagrammatic structure of the revised Wilson and Cleary model (Ferrans et al 2005). In 2005, Ferrans and colleagues revised the Wilson and Cleary conceptual model for HRQoL. In the revised model, arrows were added to show that biological function is influenced by both characteristics of the environment and the individual. In the original model, the non-medical factors (education, security, housing and employment) depict as independently influencing the overall QoL. In the revised model, these factors have been incorporated into characteristics of the environment or the individual (Bakas et al 2012, Ferrans et al 2005).

The revised Wilson and Cleary model has five endogenous components and two exogenous components. The endogenous components include the biological function, symptom status, functional status, general health perceptions and overall QoL. The exogenous components are made up of the characteristics of the individual and environment. The endogenous

components are those latent variables that are dependent or influenced by one or more components within the model while the exogenous components are those that are independent or are not influenced by any component within the model. As hypothesised by the revised Wilson and Cleary model, the characteristics of the individual and environment influence or both have a direct effect on biological function, symptom status, functional status, general health perception and overall QoL (Ferrans et al 2005). The biological function has a direct effect on symptom status. The biological function has an indirect effect on overall QoL through symptom status, functional status and general health perceptions. Symptom status has a direct effect on functional status, and symptom status also affects the overall quality of life indirectly through both functional status and general health. Similarly, functional status has a direct effect on general health perception, and functional status affects overall QoL indirect through general health. Finally, general health perception has a direct effect on overall QoL (Ferrans et al 2005, Wilson & Cleary 1995).

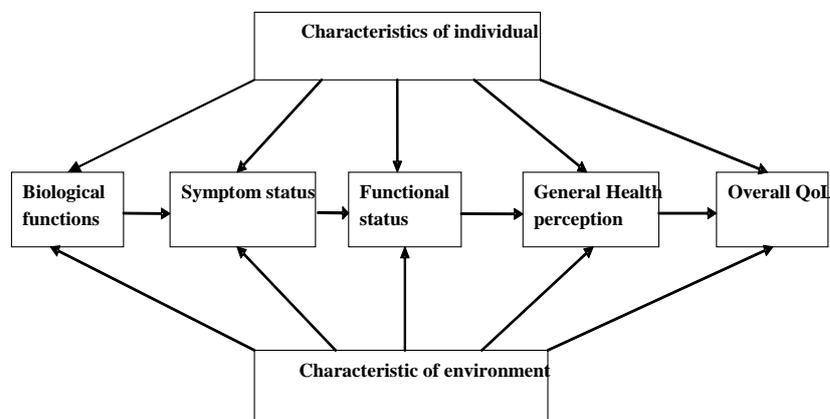


Figure 1.4 The revised Wilson and Cleary model

Undoubtedly, the use of a conceptual model such as Wilson and Cleary model to assess HRQoL provides a more comprehensive validated understanding of the pattern of the impact

of a certain disease on HRQoL of an individual or population (Sousa & Kwok 2006, Sousa et al 1999, Vallerand et al 1998). Furthermore, the use of the model to assess HRQoL also helps the researchers to appreciate the relationship among the QoL concepts to evaluate the relative importance of different approaches to patient care (Wilson & Cleary 1995). Recently, the revised Wilson and Cleary model has been applied to assess HRQoL of various chronic diseases such as type-2 diabetes (Chia 2007), coronary artery disease (Ulvik et al 2008), kidney disease (Kring 2008) and lumbar spinal surgery (Saban et al 2007) patients in the USA, but it has not been applied to HIV and in Nigeria. HIV differs from type-2 diabetes, coronary heart disease and kidney disease regarding mode of transmission, associated symptoms, how each of them affects functional status, general health perception and overall QoL.

Even though HIV infection has no cure, however, the existence of pharmacological regimens has played an important role in prolonging the life of PLWHA (McDonnell et al 2000). As depicted in several literatures ART impacts on HRQoL of PLWHA (Mwesigire et al 2015, Safren et al 2012, Zubaran et al 2014, Ming et al 2012). The provision of effective ART has considerably reduced both mortality and morbidity among PLWHA (Carballo et al 2004, Murri et al 2003, Cederfjäll et al 2001) and also changed the HIV/AIDS from being an acute fatal condition to a manageable long-term illness (Garvie et al 2009, Stangl et al 2007, Mrus et al 2006). However, despite longer longevity and improved availability of ARV drugs for PLWHA, their well-being remains affected due to a high degree of psychological distress (Duracinsky et al 2012a), social, economic, and physical health problems (Folasire et al 2012). Several literatures have shown that discrimination (Peltzer & Ramlagan 2011, Ho et al 2010, Ogbuji & Oke 2010), stigma (Charles et al 2012, Rao et al 2012, Li et al 2011, Thomas et al 2005), fear of death (Duracinsky et al 2012a), ARV drugs adverse effects (Brent 2012, Cooper et al 2011) and comorbidities such as tuberculosis (Kittikraisak et al 2012, Deribew et

al 2009) and chronic liver diseases (Henderson et al 2012, 2008, Briongos Figuero et al 2011) may have debilitating effects on the HRQoL of PLWHA.

The traditional clinical way of assessing change in PLWHA has focused mainly on a laboratory test of biomarkers such as CD4+ count, viral load etc. which give vital information about the disease severity and progression rather than the patient's perception of change. For HRQoL, however, it is difficult to make a distinction between the physical impact of HIV and an individual's personal and social context due to the effect of HIV on social aspects of life (Higginson & Carr 2001).

Because HIV affects and is affected by broader aspects of PLWHA lives (physical and social functioning, psychological well-being and relationships), information on these aspects could be used to influence treatment decisions and assessment of health needs of the population. The increased life expectancy and reduced morbidity among PLWHA make QoL a key outcome measure for patients and for providers of medical and social services because it provides information on a range of problems and also helps to identify the major problems to prioritise (Garvie et al 2009, McDonnell et al 2000) in order to optimise function and well-being (Murri et al 2003). Together with biological end-points, HRQoL is an essential outcome measure and a clinical indicator of patient well-being that can help to facilitate communication between patients and healthcare providers (Andrinopoulos et al 2011). Also, it helps the researchers to inform health and social policymakers about the impact of the disease, treatment and services including factors influencing important components of patient life to influence clinical decision making (Andrinopoulos et al 2011).

QoL is highly subjective and unique to each person, determined by experience, personal beliefs and value, culture. Nigeria is a multicultural state and the second largest country in sub-Saharan Africa with the burden of HIV. Thus, it is imperative to use a robust and

comprehensive approach to assess HRQoL in PLWHA. The use of the revised Wilson and Cleary model in this study was to provide a better understanding of the pattern of the relationships between QoL domains. Further, as discussed above, characteristics of the environment have a direct impact on overall QoL. The security challenges in North-eastern Nigeria form one of the physical elements of the characteristics of the environment. Therefore, it has provided an opportunity to test the model in a conflict setting. It has not been tested in this setting before as most of the previous studies that have used the model were conducted in the high-income countries without extreme political conflict. This means that this study has potential to add new knowledge about assessing QoL among PLWHA living in a conflict area in a resource-limited setting. It also has the potential to suggest modifications to the Wilson-Cleary model to make it an appropriate framework for studying QoL in this setting.

The next is the literature review chapter; it will provide the findings of the existing literature.

Chapter Two

Literature review

Introduction

The last chapter (chapter one) provided the background of the study. In this chapter, the results of a systematic review of the literature that examines HRQoL in a global and Nigerian context are discussed. This review was undertaken to identify gaps in the literature. Taking this into account, the potential contribution of this research is identified as well as its relevance is discussed in this chapter. Finally, the aims and objectives of the study are laid out.

Method of reviewing literature that assessed HRQoL in PLWHA

A systematic literature review was conducted to review studies that assessed and explored HRQoL in PLWHA. A systematic review was conducted because it is the best approach with least bias to evaluate research evidence and to identify existing gaps in the literature (Bowling 2017, Aveyard 2010, Higgins & Green 2008, Khan et al 2003). A systematic literature review assists in synthesising, appraising, and choosing quality evidence (Bowling 2009, Bowling & Ebrahim 2007) and provides one of the most reliable forms of evidence-based literature through the integration of all reliable evidence accessible (Griffiths 2009, Higgins & Green 2008).

The systematic review was conducted based on Cochrane Collaboration guidelines (Wieseler & McGauran 2011). These guidelines include the following stages: identifying research question; identifying articles based on pre-defined inclusion and exclusion criteria; an explicit search strategy; adoption of principle for article for the review; critical appraisal of literature based on a defined method; and synthesizing and presenting findings (Higgins & Green 2011, 2008, Wieseler & McGauran 2011, Bjordal et al 2005).

Inclusion and exclusion criteria

Both quantitative and qualitative research that assessed HRQoL among PLWHA aged 18 years and older written in English language were included. Studies that were not written in English and studies conducted among PLWHA less 18 years old are excluded in this review. For the quantitative literature only studies that addressed aspects of the Wilson and Cleary HRQoL model were included. Further, studies conducted in Nigeria were initially restricted to aspects included in the Wilson and Cleary HRQoL model and later expanded to include also those studies conducted in Nigeria to assess HRQoL among PLWHA more broadly, i.e. without the use of the model.

Search strategy

Four electronic databases (Medline, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PubMed and Web of Science) were searched systematically. The keywords used in each of the databases include: ‘Quality of life’; ‘health-related quality of life’; QOL; ‘HRQOL; HQOL; ‘human immunodeficiency virus’; ‘HIV infection’; HIV; HIV/AIDS; “Wilson and Cleary model”; “Conceptual framework”; “Conceptual model; ‘qualitative research’; and Nigeria (Table 2.1 shows the summary of the keywords). Boolean operators, I (OR and AND) were used to combine search terms and separate concepts to retrieve the relevant articles. The ‘OR’ was used to broaden the search by connecting two or more synonyms to retrieve results containing either or all the search terms. For example, Quality of life’ OR ‘health-related quality of life’ OR QOL; OR ‘HRQOL; OR HQOL. The ‘AND’ was used to combine two or more different search terms to narrow the search to retrieve data that contained only the combined search terms. For example, ‘Quality of life’ AND HIV AND Nigeria. Table 2.2 shows how the keywords were combined. The search was restricted to between 1996 and 2016 because the Wilson and Cleary model was first used to assess HRQoL in HIV in 1996. Also, there was no effective ART before 1996. The details of

how the aforementioned keywords were combined and interchanged throughout the search are shown in appendix I.

Table 2.1: Search terms used to identify the relevant studies

Search Term
1. 'Quality of life'
2. 'Health related quality of life'
3. QOL
4. HRQOL
5. HQOL
6. 'Human immunodeficiency virus'
7. 'HIV infection'
8. HIV
9. HIV/AIDS
10. 'Qualitative research'
11. 'Qualitative study'
12. 'Wilson and Cleary model'
13. 'Conceptual framework'
14. 'Conceptual model'
15. Nigeria

Table 2.2 Combination of Keywords to search for studies

Search number	Keywords combination
1	"Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL
2	"Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS"
3	"Wilson and Cleary model" OR "conceptual framework" OR "conceptual model"
4	1 AND 2
5	1 AND 2 AND 3
6	1 AND 2 AND 3 and Nigeria
7	1 AND 2 AND Nigeria
8	1 AND 2 AND "Qualitative research" OR "qualitative study"
9	1 AND 2 AND "Qualitative research" OR "qualitative study" AND Nigeria

In addition to the database search, a grey literature search (scanning of relevant websites such as International AIDS Society Conference and the Conference on Retroviruses and Opportunistic Infections), citation searching (technique focuses on identifying websites where previous articles are published), footnote chasing (technique was used to identify useful information by searching the reference section of other papers), and subject index search (search library shelves, journal indexes, bibliographic descriptions of titles, abstracts and authors of a document) were also conducted to identify relevant literature.

Sifting of the literature

The relevant studies retrieved from each electronic database were filtered manually in three stages. In the first stage, the title of studies that met the inclusion criteria was sifted to include only relevant study titles. In the second stage, the abstracts of each of the qualified studies were further examined for relevance, and only abstracts with relevant information were considered. The third stage included a full-text examination of these studies. Studies that examined QoL among caregivers of PLWHA, children living with HIV or other chronic diseases such as tuberculosis, diabetes, and kidney disease were considered irrelevant and were excluded. The reference lists of the relevant studies were reviewed and relevant literatures identified were snowballed. Figure 2.3 shows a flowchart summarising the steps used in the sifting through the studies to identify those that were relevant.

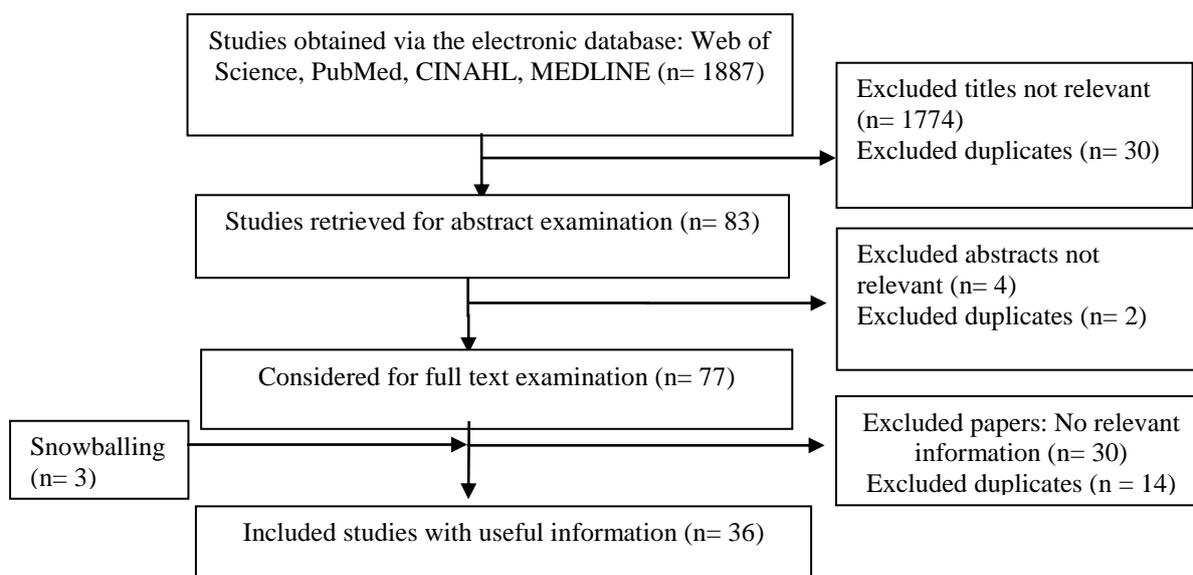


Figure 2.1 Flowchart showing sifting strategy

The systematic literature review included both quantitative and qualitative studies about HRQoL in PLWHA aged 18 years and older. Out of the 36 studies included, twelve studies were those that used Wilson and Cleary conceptual model to assess QoL in HIV, thirteen were qualitative studies (two were from Nigeria), two were systematic reviews of qualitative studies, one study was mixed-method research, and eight were quantitative studies conducted in Nigeria. The studies included in the two systematic reviews (Chambers et al 2015 and Barroso & Powell 2000) were not captured during the literature search of this current study probably because of differences in the search terms used which reflects the aims of the various studies. For instance, Chambers et al (2015) aimed to explore the intersections of stigma and health for PLWA, and their search terms were ‘stigma, ostracism, prejudice, stereotyping, HIV and human deficiency virus among others’. Reference chasing of these two systematic reviews did not provide any additional studies to be included. Table 2.4 gives

details of quantitative studies that used the Wilson and Cleary conceptual model. Table 2.5 gives details of the qualitative and mixed method studies. Details of the Nigerian studies are in Table 2.6 which is presented later in this chapter. The presentation of the quantitative and qualitative studies in separate tables is to facilitate separate critiques of these studies. However, discussion of the findings integrates the quantitative and qualitative studies.

All the studies obtained from full-text examination were critically appraised using the appropriate critical appraisal skill programme (CASP) tool based on the corresponding type of research design (Higgins & Green 2011, Bowling & Ebrahim 2007). CASP tools are designed to address the principles behind the study types with a particular interest in assessing the robustness of a study (Higgins & Green 2011, Aveyard 2010).

Data extraction

Total of 1887 studies were first retrieved from the entire databases search. However, only 36 studies met the inclusion criteria (PubMed - 380; CINAHL- 32; Medline - 613; and Web of Science – 844). Initially synonyms of “quality of life” were labelled as search one; HIV as search two; and “Wilson and Cleary model as search three” were separately inserted into the each of the databases, a large number of outputs were generated beyond management. Synonyms of each keyword were combined with Boolean’s Operator I “OR”. Secondly, to reduce output to a manageable size/number, search one and two were combined in each of the databases with a Boolean’s Operator I “AND”. After putting in the limiters, that is, papers published between 1996 and 2016, and published in English language. Still, the outputs were beyond management. Thirdly, search one, two and three were combined using the “AND” Boolean’s Operator and adding all the limiters, the outputs came down to a manageable number in each of the databases. The details of how the keywords mentioned above were combined and interchanged throughout the search for each database are shown in appendix I.

Lastly, manual search of relevant papers was conducted and also duplicated papers were removed. Table 2.3 shows the summary of the outputs came down to a manageable number in each of the databases.

Table 2.3 Summary of the outputs came down to a manageable number in each of the database (1996-2016)

Search number	Keywords combination	PubMed	Medline	CINAHL	Web of Science
1	("Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL) AND ("Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS") AND ("Wilson and Cleary" OR "conceptual framework" OR "conceptual model")	380	613	3	844
2	("Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL) AND ("Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS") AND ("Wilson and Cleary" OR "conceptual framework" OR "conceptual model") AND Nigeria	1	4	0	0
3	("Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL) AND ("Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS") AND Nigeria	58	64	17	29
4	("Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL) AND ("Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS") AND ("Qualitative research" OR "qualitative study")	133	132	32	181
5	("Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL) AND ("Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS") AND ("Qualitative research" OR "qualitative study") AND Nigeria	2	2	0	3

Table 2.4: Summary of the studies that used Wilson and Cleary conceptual model to assess HRQoL

S/No	Author	Location	Population	Findings	Strengths	Weakness
1	Henderson et al (2012) Secondary data analysis	USA	523	The Wilson and Cleary model was found to be useful in linking clinical indicators to HRQoL.	1-Sample size was relatively large. 2-Adjusted result for potential confounders. 3-Used HIV-specific QoL instrument (MOS-HIV).	1-Did not clearly mention the data cleansing process. 2- Did not explain details of how participants were recruited from the database (1999-2007).
2	Nokes et al (2011) Cross sectional study	USA	1217	Body change distress, AIDS diagnosis, age, and depressive symptoms were independent predictors of sexual functioning as a measure of physical functioning in PLWHA.	1-Multicentre study. 2-Population size relatively large. 3-Used HIV-specific QoL measure (HAT-QOL) 4-Adjusted results for confounders.	1-Used purposive sampling 2-Did not conduct power calculation. 3. Variation in sample size between the study sites.
3	Ryu et al (2009) Secondary data analysis	USA	956	PLWHA with fewer symptoms had significant increased functional status.	Population size was relatively large.	1-Data was collected between 1992 and 1994 prior to the introduction of effective ARVs in 1998. 2-Did not adjust results for potential confounders. 3-Data cleansing process was not clearly discussed. 4-Used generic QoL instrument (HDI).
4	Sousa & Kwok (2006) Secondary data analysis	USA	917	The relationships between the Wilson and Cleary's model constructs were all significant and the model adequately fits the data.	1-Sample size was relatively large. 2-Adjusted result for potential confounders.	1-The sample used in this study were only males 2- Data was collected between 1992 and 1994 prior to the introduction of effective ARVs in 1998. 3- Data cleansing process was not clearly discussed. 4-Used generic QoL measure (HDI).
5	Phaladze et al (2005) Cross sectional study	Swaziland, South Africa, Lesotho & Botswana	743	PLWHA with lower symptom intensity had greater functioning and had fewer health worries.	1-Multicentre study. 2- Population size relatively large. 3-Used HIV-specific instrument (HAT-QOL). 3- Adjusted result for potential confounders (comorbidities)	1-Used purposive sampling 2-Did not conduct power calculation.

Table 2.4: Summary of the studies that used Wilson and Cleary conceptual model to assess HRQoL...continued

S/No	Author	Location	Population	Findings	Strengths	Weakness
6	Portillo et al (2005) Cross sectional study	US, Norway, Taiwan, Colombia and Puerto Rico	1217	Individual characteristics, environment, physiological factors, symptom status, functional status, and general health perceptions made statistically significant contributions to life satisfaction.	1-Multicentre study. 2- Population size relatively large. 3-Used HIV-specific instrument (HAT-QOL). 3- Adjusted result for potential confounders.	1-Used purposive sampling 2-Did not conduct power calculation.
7	Clingerman et al (2004) Cross sectional study	USA	78	Frequent participation of moderate to vigorous physical activity at least 30 minute 3-4 days per week was moderately and significantly correlated with HRQoL. Friends support was significantly correlated with HRQoL.	Used HIV-specific QoL instrument (MOS-HIV).	1-Population size relatively small. 2-Used purposive sampling 3-Did not conduct power calculation. 4-Did not adjust result for potential confounders.
8	Nokes et al (2000) Cross sectional study	USA	713	Older PLWHA (≥ 50 years) reported significant physical functioning limitation and better self-disclosure of HIV status than younger participants (<50 years).	1-Population size was relatively large. 2- Used HIV-specific QoL instrument (HAT-QOL)	1-Used purposive sampling. 2-Did not conduct power calculation. 3-Did not adjust result for potential confounders.
9	Cosby et al (2000) Secondary data analysis	USA	146	Higher CD4+ count significantly associated with better symptom scores measured by anaemia.	Adjusted results for confounders.	1-Sample size was relatively small. 2- The data was extracted from the Quality of Nursing Care of People with AIDS Study (1989–1997) that was collected prior to the provision of effective ARVs 3- Data cleansing process was not clearly discussed. 4-Used generic QoL measure- MOS-36 5-Instead of CD4+ counts or viral load, anaemia was used as biological variable but anaemia itself is comorbidity.

Table 2.4: Summary of the studies that used Wilson and Cleary conceptual model to assess HRQoL...continued

S/No	Author	Location	Population	Findings	Strengths	Weakness
10	Sousa et al (1999) Cross sectional study	USA	142	Symptom status, functional status and general health perception were significant predictors of overall QoL.	1- Adjusted result for confounders.	1- Population size was relatively small. 2-Used purposive sampling 3-Did not conduct power calculation. 4-Used generic QoL instrument (MOS-30).
11	Wilson & Cleary (1997) Cohort study	USA	305	Symptoms status was an independent significant predictor of independent activity of daily living (IADL).	1- Adjusted result for potential confounders. 2-Population size was relatively large.	1-Used generic QoL instrument (MOS 36). 2-Used purposive sampling. 3-Did not conduct power calculation. 4-The study was conducted before the introduction of highly active ARV therapy
12	Wilson & Cleary (1996)	USA	305	Symptom reports were strong predictors of physical functioning.	1- Adjusted result for potential confounders. 2-Population size was relatively large.	1-Used generic QoL instrument (MOS 36). 2-Used purposive sampling. 3-Did not conduct power calculation. 4-The study was conducted before the introduction of highly active ARV therapy.

Table 2.5: Summary of the qualitative studies that explored HRQoL in HIV**The overall aim of the studies was to explore HRQoL among PLWHA aged 18 years and above and the general exposure is HIV infection**

S/No	Author	Location	Population	Method	Findings	Strength	Weakness
1	Alomepe et al (2016)	Cameroon	30	Method not explicitly mentioned but used semi-structured in-depth interview	Living with HIV is a constant life struggle and QoL is negatively affected by limited resources and support as well as stigma.	1-Interviews were audio recorded. 2-Findings were peer-reviewed by authors and used to respondents to verify results.	
2	Chambers et al (2015)	Not applicable	Not applicable	Systematic review	HIV associated stigma within health context is a broad social phenomenon that manifest with several social sphere and social support, advocacy, self-efficacy, education and resilience activities were strategies employed in managing stigma among PLWHA.	1-The electronic databases used to obtain data were mentioned. 2-Keywords used were mentioned. 3-Inclusion criteria clearly mentioned. 4-Findings were geographically diverse (Western and non-Western). 5-Data were peer-reviewed by the authors.	1-Only studies in English were included. 2- The criteria which the data were critically appraised was not clearly mention.
3	Mutabaz-Mwesigire et al (2014)	Uganda	20	Method not explicitly mentioned but used in-depth interview	QoL is being happy all the time. Stigma, fears of disclosure and poverty negatively affect QoL.	1-Findings were peer-reviewed by the authors 2-Findings were visited and verified with participants in follow-up interview.	1-Interviews not audio recorded.
4	Herrmann et al (2013)	Australia	15	Mixed methods and used semi-structured in-depth interview	QoL was negatively affected by emotional distress, poor physical health, stigma and ARVs side effects. QoL means being happy at all time and have a good social relationship with family and friends.	1-Data were peer-reviewed by the two of the authors 2-Used respondents to discuss the credibility of findings.	

Table 2.5: Summary of the qualitative and mixed methods studies that explored HRQoL in HIV...continued

S/no	Author	Location	Population	Method	Key findings	Strength	Weakness
5	Dibb & Kamalesh (2012)	UK	12 African women	Phenomenological approach using semi-structured interview	Coping and interpretation of situation; behavioural changes; adaptation; value of life; and changes in goals and opportunities are found to shape general QoL.	1-Semi-structured interview.	1-Used note taking only for data collection. 2-Did not discuss how the credibility of the findings was assessed.
6	Ming et al (2012)	China	20	Method not explicitly mentioned but used semi-structured interview/open-ended questions	Psychological burden of taking drugs, and the fear of accidental transmission to others, or disclosure of HIV status known negatively affect well-being.	1. Used respondents to discuss the credibility of findings.	-Used note taking only for data collection.
7	Chen et al (2011)	China	26 Chinese women	Phenomenological approach using individual in-depth interview	Stigma, disclosure of HIV status, lack of social support, and family life affect well-being.	Audio taped the interview and transcribed verbatim.	1-Did not clearly mention how the credibility of the findings was assessed.
8	Adedimeji et al (2010)	Nigeria	50	Grounded theory using in-depth interview	Family commitments and children's welfare, stigma, financial constraints, drug, treatment and health services accessibility and Care support negatively affects overall being.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of findings. 2-Included PLWHA (80%), health care providers, and caregivers as participants and all the data were matched.	
9	Ho et al (2010)	Hong Kong	36	Method not explicitly mentioned but used individual interviews	Adaptation/coping; physical health; stigma/discrimination; HIV care services; ARV therapy; sexual relationships; family and friends' relationships; work and money; defined overall QoL.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of findings.	

Table 2.5: Summary of the qualitative and mixed methods studies that explored HRQoL in HIV...continued

S/no	Author	Location	Population	Method	Key findings	Strength	Weakness
10	Ogbuji & Oke (2010)	Nigeria	21	Method not explicitly mentioned but used focus group & in-depth interview	Stigma and discrimination, economic hardship, lack of job, coping, spiritual/religious belief, and social relationship (family/friends) influenced QoL.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of findings.	
11	Groft & Robinson (2007)	Canada	7	Method not explicitly mentioned but used individual interviews	Coping, spirituality, future and health care provider's attitude influenced the well-being of PLWHA.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of the findings. (
12	Park-Wyllie et al (2007)	Canada	38	Grounded theory using focus group with semi-structured interview	ARV side effects, relationship with health care providers, adherence; disclosure, stigma, sex, sleep, future, coping, and income affect QoL.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of findings.	1-Used note taking only for data collection.
13	Geurtsen (2005)	Cambodia	25 (15 females & 10 males)	Ethnography using semi-structured interview	Ability to maintain life functioning; isolation and desire for connection; disclosure; coping; adaptation; anticipating the future; family/friends relationship; care; and reflection influenced QoL in PLWHA.	1-Audio taped the interview and transcribed verbatim. 2-Used respondents to discuss the credibility of findings.	
14	Power et al (2003)	UK	14	Grounded-theory using in-depth interview	Lipodystrophy has negative physical effects, psychological effects, sexual and social functioning reduced well-being among PLWHA.	1-Audio taped the interview and transcribed verbatim. 2-Used triangulation to discuss the credibility of findings.	

Table 2.5: Summary of the qualitative and mixed methods studies that explored HRQoL in HIV...continued

S/no	Author	Location	Population	Method	Key findings	Strength	Weakness
15	Barroso & Powell-Cope (2000)	Not applicable	Not applicable	Systematic review of qualitative studies	Finding meaning in HIV/AIDS, coping, family, friends & community relationships and stigma affect QoL.	1-Used Burns's (1989) standard for qualitative research was said to have been used to evaluate the rigor of the included studies. 2-Data were peer-reviewed by the authors.	1-Used electronic databases to generate data, however, the database(s) and the key words used were not clearly mentioned. 2-Studies included were those conducted before ARVs used. 3-Only studies in English language were included
16	Testa & Lenderking (1999)	USA	34	Method not explicitly mentioned but used focus group/semi-structured interview	Symptoms and perceptions of body wasting, poor physical, psychological and social functioning, and poor sexual functioning effect QoL.	Audio taped the interview and transcribed verbatim.	Did not clearly mention how the credibility data the data was assessed.

Critique of the quantitative studies that used Wilson and Cleary conceptual model to assess HRQoL

The twelve quantitative studies in Table 2.4 that used the Wilson and Cleary model to assess QoL in PLWHA were reviewed, and all had identifiable weaknesses, mainly due to issues of using cross-sectional study design, recruitment and sample size which is to be expected with studies of PLWHA because of HIV related perceive social stigma. The studies by Wilson & Cleary (1996, 1997) were judged to be relatively strong because they were cohort studies that facilitate stronger inference of causal effects between variables.

The studies by Nokes et al (2000, 2011), Portillo et al (2005), Phaladze et al (2005), Clingerman et al (2004) and Sousa et al (1999) are all cross-sectional studies. Cross-sectional studies do not provide strong evidence for causal relationships between variables. Therefore, it is difficult to disentangle the cause and effect of HIV infection on HRQoL. A longitudinal study addresses some of the issues with cross-sectional studies. A longitudinal study is particularly suitable for assessing causal relationships between risk factors and the development of disease, and the outcomes of treatments over different lengths of time (Caruana et al 2015). Likewise, because data is collected for given individuals within a predefined group, appropriate statistical testing may be employed to analyse change over time for the group as a whole, or for particular individuals (Caruana et al 2015). However, it is costly; it requires enormous amounts of time and large sample size to conduct.

The major issue is the timing of the study and when the data were collected given the rapid advance in ARV treatments and the clear impact of ARVs on the QoL of PLWHA. Four of the studies (Henderson et al 2012, Ryu et al 2009, Sousa & Kwok 2006, Cosby et al 2000) which were secondary data analysis used data that were collected before 1996 when ARVs were not common. For instance, Henderson et al (2012) explicitly mentioned that the information from their sample did not capture the impact of ARV drugs on QoL because

only few participants had access to combination ARVs at the time of their data collection. Their findings may not apply to the present reality where most people diagnosed with HIV have access to effective ART in the USA and other Western countries with similar socioeconomic status. Thus, the generalisability of the findings of their analysis may be limited because their results may not apply to PLWHA in this present time where there is improved access to effective ART around the globe. Also, the process of data cleansing was not clearly mentioned in all the four secondary data analysis. Thus, this may have affected the validity and reliability of their findings (Flowerdew & Martin 2005).

Specifically, on recruitment technique, eight studies (Nokes et al 2011, Phaladze et al 2005, Portillo et al 2005, Clingerman et al 2004, Nokes et al 2000, Sousa et al 1999, Wilson & Cleary 1997, Wilson & Cleary 1996) purposively recruited their participants which incur a risk of selection bias. The use of purposive sampling techniques may not give a true representation of the population, therefore; the findings of these studies may not be generalisable. Although, random sampling technique to recruit participants could have been the best approach to obtain a true representative of a sample, in setting where HIV related stigma prevails, many PLWHA may not like to participate in a study because they may see it as a way of disclosing their HIV status. In this situation, random sampling may be difficult.

The sample sizes in the studies by Henderson et al (2012), Ryu et al (2009), Sousa & Kwok (2006), Portillo et al (2005), Phaladze et al (2005), Nokes et al (2011) and Wilson & Cleary (1996, 1997) were relatively large. For instance, Henderson et al (2012), Nokes et al (2011), Sousa & Kwok (2006) and Wilson & Cleary (1996, 1997) conducted power calculations to estimate their sample size to achieve 80% statistical power. However, the sample sizes of the studies by Clingerman et al (2004), Cosby et al (2000) and Sousa et al (1999) were

relatively small, and the statistical power of these studies was less than 80%, probably due to their small sample size (Peter & Bennett 2012).

A number of studies used a generic QoL measure rather than an HIV-specific one to assess HRQoL of their participants. Four studies (Cosby et al 2000, Sousa et al 1999, Wilson & Cleary 1996, 1997) used the MOS-SF36. Also, Ryu et al (2009) and Sousa & Kwok (2006) used Health Assessment Questionnaire-Disability (HAQ-DI) which is a generic QoL measure. The use of generic QoL instruments may not be able to capture disease-specific HRQoL (Palfreyman 2011, Rapley 2007) therefore, these instruments are at risk of providing results with either ceiling- or floor-effects of the impact of HIV on QoL among their participants. The remaining six studies (Henderson et al 2012, Nokes et al 2000, 2011, Phaladze et al 2005, Portillo et al 2005, Clingerman et al 2004) used HIV-specific measures to assess QoL, for example, MOS-HIV and HAT-QOL questionnaire. However, these measures were developed before the introduction of ARV drugs the impact of the ARV drugs on HRQoL will not be captured by these instruments (Duracinsky et al 2012a). Therefore, there is the need for the use of HIV-specific instruments that have been developed during the ARV era such as the PROQOL-HIV questionnaire.

In Table 2.4, all the quantitative studies included provided an explicit in-depth description of the data analysis process. Henderson et al (2012), Sousa & Kwok (2006), Portillo et al (2005), Sousa et al (1999) and Wilson & Cleary (1996, 1997) adjusted their results for potential confounding factors such as age, gender, education, income and time since HIV diagnosis. However, other potential confounders such as comorbidities (tuberculosis, hepatitis, diabetes), smoking, alcohol use, were not adjusted for. Studies have shown that HIV infected persons with comorbidities had significantly worse QoL compared to mono HIV infected person (Henderson et al 2012, 2008, Deribew et al 2009). Phaladze et al (2005) adjusted results for potential confounders (comorbidities) but did not explicitly

mention which comorbidities were adjusted for in their results. Ryu et al (2009), Clingerman et al (2004), Nokes et al (2000, 2011) and Cosby et al (2000) did not adjust results for potential confounders, and this poses a risk of confounder bias which limits generalisability of their results.

Sousa et al (1999) conducted a path analysis. Sousa and colleagues included fifteen dummy coded variables (categorical variable) which measured characteristics of the individual and environment into their analysis. In dummy variables, an assumption of normality is mostly not assumed nor are the remaining terms related to them. Thus, standard assumption of linearity of multiple data point may be biased, making it less likely for the authors to find a significant effect of the dummy variables in the analysis (Allen & Bennett 2012, Cohen 2003). Sousa et al (1999) put it that the use of too many dummy variables in a smaller sample may have placed limitations on their findings due to an aggregated path coefficient was replaced with change in R² (proportion of variance in the criterion that can be accounted for by the predictor variables in the regression model) as the dummy variables were entered into the model. It can be argued that the small sample size of the study of Sousa et al (1999) could not handle the dummy variables generated because of small degrees of freedom which limited making a conclusion regarding lack of effects of the characteristics of the individual and environment shown in the regression model of path analysis.

Except for the study by Phaladze et al (2005) which was conducted in South Africa, all of the studies reviewed were conducted in the USA. The findings of these studies may not apply to other settings such as countries with limited resources due to differences in demography, income and access to healthcare.

Critique of the qualitative studies

The sixteen qualitative studies in Table 2.5 explored the impact of HIV on QoL among PLWHA, and all had identifiable weaknesses, mainly due to issues of data collection, recruitment and data analysis. Critical appraisal tool for qualitative studies (Treloar et al 2000) and Yardley's criteria for evaluating qualitative research (Yardley 2000) were used to assess strengths and weaknesses of the qualitative studies. All the qualitative studies explicitly mentioned that data collection took place in a quiet private place with no third party present. The private use place is vital because HIV/AIDS is a disease highly associated with stigma and use of a private place will assist the researchers to gain the participants confidence to freely speak in detail about their life experience of living with the illness and how it affects their QoL.

The studies by Chambers et al (2015) and Barroso & Powell-Cope (2000) were judged to be relatively strong because they were systematic reviews. The advantage of systematic reviews of qualitative studies is that they involve the collation and interpretation of published findings from multiple studies. This helps to capture the essence of the impact of HIV on QoL of PLWHA from different settings and therefore provides stronger evidence and better understanding than an individual study. The systematic review by Chambers et al (2015) and Barroso & Powell-Cope (2000) only included articles written in English. Barroso & Powell-Cope (2000) used Burns's (1989) criteria for evaluation of qualitative research to critically appraise the rigour of the included studies. However, Chambers et al (2015) did not explicitly mention how the data were critically appraised. In each of the systematic reviews, data were peer-reviewed and clearly presented. Barroso & Powell-Cope (2000) say that they used electronic databases to generate data. However, the database(s) and the keywords used were not mentioned, this makes the replication of the study impossible. Barroso & Powell-Cope only included studies conducted in the USA. One of the

limitations of the study by Barroso & Powell-Cope (2000) is the non-inclusion of studies from middle income and developing countries; the authors explicitly mention that the experience of living with HIV in the USA differs substantially compared with those in the developing countries, and this may limit the generalisability of their findings. However, the databases and the keywords used by Chambers et al (2015) were explicitly stated. Nevertheless, the use of mono-lingual studies limits the validity and reliability of their findings.

Three studies (Dibb & Kamalesh 2012, Chen et al 2011, Testa & Lenderking 1999) were judged to be weak because they did not mention explicitly how the credibility of their findings was ensured. Credibility in qualitative research is the rigour of establishing results of a study that is believable. Credibility is ensured through peer debriefing, prolonged engagement with the participants (to build trust and understand the culture, social setting or phenomenon of interest), member-checking and triangulation.

Also, the studies by Ogbuji & Oke (2010) and Park-Wyllie et al (2007) were judged to be weak because they did not clearly discuss how they were able overcome dominance by some participants during the focus group interview session. However, using a focus group when properly applied may be an excellent way to collect much richer data as it is often a good way to get participants to talk in a natural setting to each other.

The process of establishing trust and relationship with participants are important in ensuring credibility in qualitative study (Yardley 2000). As such, seven of the included qualitative studies (Alomepe et al 2016, Mutabaz-Mwesigire et al 2014, Dibb & Kamalesh 2012, Ming et al 2012, Ho et al 2010, Ogbuji & Oke 2010, Chen et al 2011, Park-Wyllie et al 2007, Geurtsen 2005) did not explicitly mention how they establish trust and relationship with their participants. In addition, these studies did not discuss how the researchers'/authors'

position such as gender, race, HIV status, experience, views etc influence how their participants were recruited and how the data were collected. Therefore, these limit the credibility of their findings.

In all the qualitative studies reviewed the authors did not mention how their preconceptions, beliefs, values, and assumptions may have influenced the research process.

It is worth noting that including multiple researchers qualitative study helps in promoting dialogue, harmony and understandings of divergent ideas of a study situation including the provision of a context in which the researchers' - often hidden beliefs, values, perspectives and assumptions can be revealed and contested. In this literature review, all the included qualitative studies involved multiple investigators and they explicitly mention the role of each and how they deliberated on their data collection and analysis processes. This has helped to enhance the reliability of their findings.

Eight of the qualitative studies explicitly mentioned that they used questions related to QoL to explore the impact of HIV among participants (Alomepe et al 2016, Mutabaz-Mwesigire et al 2014, Herrmann et al 2013, Chen et al 2011, Ming et al 2012, Adedimeji et al 2010, Ho et al 2010, Geurtsen 2005). Two studies used model guided questions (Ogbuji & Oke 2010, Testa & Lenderking 1999) to explore HRQoL among participants. Topic or model guide questions help researchers to conduct a study within areas of concern to minimise the risk of out of concept coverage (Aveyard 2010). Testa & Lenderking (1999) used MOS-HIV questionnaire's questions to guide the in-depth interview session, and this may be appropriate because the questions were restricted to the concept of HIV-related QoL. The advantage of using guided question was that it had helped the researchers to keep their interview on track and also helped them gathered the required information. However, the disadvantage was that it might have made the participants not able to speak about the things

that matter to them at the time of the study. In other words, a topic guide, mainly if it is rigidly applied means that the researcher dictates what is talked.

Ogbuji & Oke (2010) used the health belief model (HBM) to guide the interview session however, HBM is a health promotion model used in developing, implementing or assessing health promotion intervention in order to improve health outcome (Siddiqui et al 2016) such as behavioural change in condom use in HIV prevention, provision or adherence of ART. The HBM proposes that a person's or group of individual's beliefs about health issues, perceived benefits of action and barriers to action and self-efficacy explain engagement (or lack of engagement) in health-promoting behaviour (Janz & Mashall 1984). The focus was thus not directly on HRQoL, and Ogbuji & Oke (2010) did not explain the link between the HBM and QoL. The researchers would have used the HBM as a theoretical framework guiding the interview rather than the participants lived experience.

Data collected were in the form of note taking (Mutabaz-Mwesigire et al 2014, Dibb & Kamalesh 2012, Ming et al 2012), audiotape recording/note taking (Chen et al 2011, Ogbuji & Oke 2010, Park-Wyllie et al 2007, Geurtsen 2005) and audiotape recording (Alomepe et al 2016, Herrmann et al 2013, Adedimeji et al 2010, Ho et al 2010, Groft & Robinson 2007, Power et al 2003, Testa & Lenderking 1999). The use of only note taking in collecting data in qualitative study poses risk of missing data. Mutabaz-Mwesigire et al (2014) acknowledge that the reason for using only note-taking to collect data was because some participants were not comfortable with audiotape recording due to stigma. Also, Mutabaz-Mwesigire et al state that not all participants freely talked about their lived experience living with HIV and few of their participants asked the interviewer not to write some points they said during the interview process. Surprisingly, Mutabaz-Mwesigire and colleagues did not mention how they overcome this barrier in their study, and this may have been due to lack of trust. This also demonstrates how the stigma of HIV can affect research, and arguably all

HIV research needs to be interpreted with this in mind. In qualitative studies of PLWHA, in particular, the high levels of stigma associated with HIV in many settings, may mean that some data is only left unsaid, for example, acknowledgement of unsafe sexual behaviour that may place others at risk of infection. On a general note, establishing trust is essential in the qualitative study especially when dealing with the vulnerable population such as PLWHA. Moreover, HIV infection is a disease that is associated with stigma in most settings. Thus, developing trust between the researcher and the participant may have helped in fostering reliability of their findings. Also, it allows the participants to talk freely, and this will help in getting rich data which will be trustworthy.

Dibb & Kamalesh (2012) and Adedimeji et al (2010) used interpretative phenomenological analysis and grounded theory to analyse their data while the rest of the qualitative studies used thematic data analysis. In general, how conflicting data were managed was not made explicit and the lack of critical discussion of how conflicting data emerged shows lack of transparency about the details of the analytic process. For instance, it was not always clear to see how themes had been identified.

Six of the qualitative studies used triangulation (researchers peer-viewed the transcript and findings and then later involved the research assistants and the respondents in verifying the findings) (Adedimeji et al 2010, Ogbuji & Oke 2010, Ho et al 2010, Groft & Robinson 2007, Park-Wyllie et al 2007, Power et al 2003) and five studies used respondent's validation (Alomepe et al 2016, Mutabaz-Mwesigire et al 2014, Herrmann et al 2013, Ming et al 2012, Geurtsen 2005) to discuss the credibility of their findings. However, Dibb & Kamalesh (2012), Chen et al (2011), Testa & Lenderking (1999) did not discuss how the credibility or quality assurance of their findings was ensured. A lack of discussion of the researcher's role in data analysis and a lack of discussion of the credibility of findings limit the extent to which one can assess the credibility of the findings.

In three studies (Alomepe et al 2016, Dibb & Kamalesh 2012, Adedimeji et al 2010), the risk of atypical samples was identified. Also, these studies did not demonstrate how they overcome the process of atypical samples selection. Dibb & Kamalesh (2012) and Adedimeji et al (2010) recruited participants through a support group. Adedimeji et al (2010) showed how stigma in the study setting influenced their recruitment. They initially opted to recruit participants from a health facility but later felt that potential participants in this setting may not be willing to disclose information about their HIV status. Recruiting participants only through a support group may have led to participants coming from a group who felt less stigmatised by HIV – that is, they were sufficiently confident to join a support group with other PLWHA. Adedimeji et al's study did not mention if any effort was made to overcome the predicted stigma to enable them to recruit from the health facility. Dibb & Kamalesh (2012) aimed to explore lived experience of African women living in the UK, but their sample size was composed of only twelve participants (six each from Uganda and Zimbabwe). Africa is multicultural and multireligious continent. Therefore, views of their participants may differ from other African women in the UK due to the subjective nature of QoL. Since participants in the study by Dibb & Kamalesh (2012) and Adedimeji et al (2010) were already registered members of an HIV support group network, therefore, their QoL could significantly differ from those not using support groups; this limits the applicability of their findings to the broader population of African women and PLWHA in South-western Nigeria and elsewhere.

The summary of the findings of the quantitative studies in Table 2.4 and qualitative studies in Table 2.5 was presented below.

Findings from the quantitative and qualitative studies

This section provides the summary of the main findings of the quantitative and qualitative literature about HIV related QoL. Although presented as two tables, the findings of the

quantitative data and qualitative data are integrated where possible. In each section, the quantitative literature is first presented followed by the qualitative literature. The findings start with a discussion about the perception of quality of life and are then presented in the domains related to the Wilson and Cleary model: biological function; symptom status; functional status; general health perception; characteristics of the individual (age, ethnicity, education, gender and disclosure/stigmatisation/discrimination); characteristics of the environment (social support, income, spirituality/coping, HIV care services and antiretroviral therapy).

Perceptions of quality of life

The evidence in this area all comes from the qualitative studies. PLWHA described QoL as having a sound general well-being which is influenced by emotional well-being, having good social relations with family and friends, having money including good health (Alomepe et al 2016, Mutabazi-Mwesigire et al 2015, Herrmann et al 2013). Some PLWHA viewed QoL as being happy and having all the basic needs of life that are, food, shelter and clothing (Mutabazi-Mwesigire et al 2015). Below are various reviews of PLWHA as how they perceived QoL:

“QoL is about being happy, availability of food, shelter, cloths and not being sick”
(A participant in Mutabazi-Mwesigire et al (2015 p.4))

“...means enjoying yourself, being happy... feeling good within yourself and about the people around you. I don't have that anymore.” (A participant in Herrmann et al 2013 p.5).

[QoL means] *life with no worries, no stress...* “...your standing in society.” “...to enjoy life...have enough money to take care of my family...” (Participants in Mutabazi-Mwesigire et al (2015 p.4))

The evidence suggests that QoL is defined in a variety of ways ranging from how happy a person is, to the ability to afford the basic needs of life (food, shelter and clothing), to how

socially connected a person is with family and friends including the position a person attends in life. Further, QoL is sometimes defined as being free from disease. Thus, this suggests that concept of QoL cannot be summed to give a single score of QoL. For example, equating QoL with happiness alone is problematic as happiness may be a marker, but not a promise, of wellness. This is because a person may be happy but not entirely physically functional.

Biological function

All the literature examining the impact of biological functions on PLWHA QoL uses quantitative measurement. It is well documented from large studies of secondary data in the USA, that PLWHA who have a lower viral load, elevated CD4+ count and are at an early HIV stage are likely to report fewer symptoms, and better functioning, and better overall QoL (Henderson et al 2012, Sousa & Kwok 2006, Portillo et al 2005). The AIDS Time-Oriented Health Outcomes Study in the USA found that lower CD4+ count was significantly related to poorer symptom status (Sousa & Kwok 2006). Using data from the National Institute of Nursing Research that was collected between April 1999 and March 2007 in the USA, Henderson et al (2012) found that higher CD4+ count significantly related to better symptom status in PLWHA. In the USA, Cosby et al (2000) conducted a study involving 146 PLWHA, using haemoglobin as a substitute measure of biological functioning, and found a lower level of haemoglobin was significantly associated with worse symptom status and lower overall QoL. However, using anaemia as a marker for a biological function is problematic as anaemia itself is one of the complications of HIV infection.

A multicentre cross-sectional study with participants drawn from 5 countries (USA, Puerto Rico, Taiwan, Norway and Columbia) involving 920 PLWHA also found that biological functioning was significantly associated with life satisfaction as a measure of overall QoL

(Portillo et al 2005). However, a survey by Phaladze et al (2005) in 4 sub-Saharan African countries (Swaziland, South Africa, Lesotho and Botswana) including 743 PLWHA reported that when using AIDS diagnosis as a surrogate measure of biological functioning it was not associated with overall QoL. In the USA, Sousa et al (1999) conducted a survey involving 142 samples of PLWHA also found that biological functioning was not related to overall QoL. The use of AIDS diagnosis as a surrogate measure of biological functioning by Phaladze et al (2005) and lack of specific type of measure of biological functioning by Sousa et al (1999) may accounted for the different findings compared to Henderson et al (2012) that used CD4+ count which is measurable and therefore more precise. The quantitative literature showing relationship between biological function and symptom status showed similar results.

Therefore, the small body of evidence that exists shows that biological functions measured by CD4+ count and viral load have an impact on symptoms status among PLWHA. It is evident that all the studies using an accurate biological marker, eg. CD4+ count shows that it is related to symptoms. The studies that do not show this all use a crude measure such as AIDS diagnosis. In many parts of sub-Saharan Africa, diagnosis often happens at a late stage, and it is therefore not a very accurate biological marker.

Symptom status

The quantitative studies in Table 2.4 show that PLWHA with more symptoms are likely to have reduced functional status and a lower perception of general health (Henderson et al 2012, Sousa et al 1999) and low or worse overall QoL (Portillo et al 2005). In the USA, Ryu et al (2009) conducted a secondary data analysis of 956 men living with HIV aimed to examine the relationships among symptoms status, functional health (disability) and QoL in PLWHA. Ryu and colleagues (2009) found that PLWHA with fewer symptoms had significantly less disability (used as a measure of functional status) which in turn is related

to better QoL. These findings correspond with the study by Sousa & Kwok (2006) who also found that PLWHA with better symptoms status significantly had better functional status and overall QoL. Similarly, Phaladze et al (2005) found that increase in the intensity of symptom status was significantly associated with reduced life satisfaction as a measure of overall QoL. In the USA, Nokes et al (2011) conducted a cross-sectional study of 1217 PLWHA and, adjusting results for potential confounders, found that higher symptom status (body change distress and depressive symptoms) was significantly associated with poorer sexual functioning as a measure of physical functioning. In the US, Wilson & Cleary (1996, 1997) conducted 8-months prospective cohort and cross-sectional study respectively involving 305 PLWHA aimed to determine clinical correlates of reduced physical functioning. They both found that fatigue and neurological symptoms were significantly correlated with reduced physical functioning in PLWHA.

Several qualitative studies found that PLWHA emphasized that symptoms such as rapid weight loss (Power et al 2003, Testa & Lenderking 1999), fatigue, lack of energy, loss of appetite (Ming et al 2012, Adedimeji et al 2010), exhaustion, night sweats, diarrhoea, fever (Ogbuji & Oke 2010, Geurtsen 2005), lack of sleep, skin lesion, loss of muscle and strength (Ho et al 2010, Park-Wyllie et al 2007) are main distressing features of HIV infection. Consistently, the qualitative literature reports that symptoms experienced by PLWHA reduce their functional status, social relationship, mental health and overall well-being (Ming et al 2012, Adedimeji et al 2010, Ogbuji & Oke 2010, Ho et al 2010). Below is testimony from participants in two of these studies:

“I have so many black spots on my legs. When people come to drink in my beer parlour, they focus their attention on my legs and I don’t feel comfortable with that. I sure they would be gossiping among themselves. At times, some bold one would ask me what is wrong with my leg. I normally tell them I have insect bite.” (A participant in Ogbuji & Oke (2010)).

“I cannot sleep. I think a lot and I am afraid to die. I think a lot about the future and what will happen to me when I am weak and sick. Every night I use a sleeping pill...I worry about many things...always tired” (A participant in Geurtsen (2005 p.46)).

Both quantitative and qualitative literature that assessed impact of symptoms on functional status reported similar results. Therefore, the large body of evidence that exists would suggest that fewer symptoms positively impact functioning among PLWHA.

Functional status

Nokes et al (2011) found that lower sexual functioning was significantly associated with higher symptoms such as body change distress and depressive symptoms after adjusting for age and AIDS diagnosis. After being diagnosed with HIV, most PLWHA express that they have less sexual pleasure, and this keeps them away from sexual activity (Ming et al 2012, Adedimeji et al 2010, Ho et al 2010, Park-Wyllie et al 2007, Geurtsen 2005, Power et al 2003, Barroso & Powell-Cope 2000, Testa & Lenderking 1999). Often time, PLWHA show concern about spreading the disease to others even with the use of condoms (Adedimeji et al 2010, Ho et al 2010). Three persons living with HIV had this testimony:

“I used to have sex once or twice a month before receiving therapy, ...but now I have less sexual desire, and have it only once every 3 to 4 months” (Ming et al (2012 p.76)).

“We have not had sex in about two years. Not his choice, my choice. He’s negative. ... After I got sick, we attempted to have safe sex, but I just couldn’t—the thought of killing him, I couldn’t handle. I still can’t” (Barroso & Powell-Cope (2000 p.347))

The quantitative literature shows that PLWHA who have high functional status scores are likely to report higher perceived general health status (Sousa & Kwok 2006) as well as better overall QoL outcome (Portillo et al 2005). Clingerman (2004) conducted a cross-section study involving 78 participants aimed to examine the relationship between physical activity, social support and HRQoL. In this study, it was found that regular weekly

participation in physical activity for a number of days for at least 30 minutes among PLWHA was significantly and moderately correlated with overall QoL.

The qualitative literature supports the impact of functional status upon QoL among PLWHAs. Living with HIV has been reported as turning every aspect of the lives of PLWHA into a constant struggle to carry out activities of daily living such as gardening, fetching water and climbing stairs due constant body weakness and fatigue (Alomepe et al 2016). A participant in Alomepe et al (2016 p.658) remarked that:

“With this HIV I am sick all the time. I can’t do much as I used to do before. I usually have body pain, running stomach, and fever. I am always feeling tired. It is my children now that cook, split wood, wash clothes and fetch water. I have giving up farming...”

Barroso & Powell-Cope (2000) conducted a systematic review of qualitative studies and found that HIV-associated body wasting and loss of energy negatively affect physical functioning such as the ability to carry out activities of daily living among PLWHA. Other factors that negatively affect physical functioning include loss of strength (Ming et al 2012, Geurtsen 2005, Testa & Lenderking 1999), devastating fatigue (Alomepe et al 2016, Ho et al 2010, Ogbuji & Oke 2010) and reduced mobility. These limit PLWHA’s ability to perform satisfactorily at work or carry out activities of daily living such as shopping, dressing and bathing, driving, using public transportation and climbing stairs thus negatively affect their QoL (Ogbuji & Oke 2010, Testa & Lenderking 1999). Some participants reveal that:

“I don’t have that energy. . . that’s what devastates me the most...as much as your mind says you can do it, your body says no... the loss of energy affected all the other areas...I can’t exercise. ...if I can do 3 [repetitions] I’m lucky, much less a set of 10” (A participant in Testa & Lenderking 1999 p.284S).

“I can’t go outside to find a job because I have to come back home every three months to get treatment...I have run out of money...My father pays no attention to me. So I just come back home to get the free medicine. I cannot go out to earn a living, and, I have contracted my farmland to others for just 400 Yuan a year” (A participant in Ming et al (2012 p.71)).

For some participants their physical functioning was limited by disability due to symptoms and comorbidity, others were limited due to lack of motivation resulting in a feeling of social isolation. A participant in Herrmann et al (2013 p.5) remarked that: *“I get tired very quick but don’t generally stop me doing anything I want to do...my problem is not wanting to do anything. . .it’s the motivation I don’t have.”*

Contrarily, Henderson et al (2012) found that there was no significant relationship between functional status and perceived general health in PLWHA. The disparity in the findings of Henderson et al (2012) and those of Sousa & Kwok (2006), Portillo et al (2005) and Clingerman et al (2004) may be due to the fact that Henderson et al’s data were collected before and during the provision of highly active ARV medication (that is between April 1999 and March 2007). It is likely that since the widespread availability of ARVs, the functional status of PLWHA has been dramatically enhanced and therefore there is less difference among PLWHA.

Other possible reasons for the disparities in the results are related to study design and sample. Henderson et al (2012), for example, conducted secondary data analysis and how data cleansing was critically conducted was not explicitly detailed. In Clingerman et al (2004) the population size was relatively small and the results were not adjusted for confounders. Sousa & Kwok included only male participants and used a generic QoL instrument to assess HRQoL in PLWHA and these pose risk of selection bias and information bias respectively.

Overall, the quantitative literature presents ambivalent evidence about the impact of functional status on general health perception. The small body of evidence that exists suggests that functional status has an impact on general health perception among PLWHA. It may also impede their HRQoL. Nevertheless, findings from qualitative studies have helped to explain some the ambivalent findings from the quantitative studies by providing a better understanding of the directions of the relationships between functional status and general health status. Also, the qualitative findings explained how HIV impacted on the functioning of the PLWHA.

General health perception

It has been argued that PLWHA with low general health perception scores are likely to have reduced or worse overall QoL (Sousa & Kwok 2006, Phaladze et al 2005, Sousa et al 1999). In contrast, Henderson et al (2012) and Portillo et al (2005) found that there was no significant relationship between health worries as a measure of perceived general health and overall QoL.

Findings from the qualitative literature are more consistent and show that PLWHA perceive their HIV status with a profound cause of the sense of sorrow and hopelessness regarding the future (Alomepe et al 2016, Adedimeji et al 2010, Ho et al 2010, Geurtsen 2005, Testa & Lenderking 1999). For instance, one participant remarked that:

“Every conversation I have turns medical. . . People come up and say ‘how are you feeling? not How are you?... I have had several people say to me that they have lost so many friends to AIDS, that they have reached a point when they see someone getting sick they want to run away from it because they don’t want to experience that loss again ...It makes me more aware of what a burden I must be” (A participant in Testa & Lenderking (1999 p. 287S)).

Therefore, the small body of evidence that exists would suggest that general health has a direct impact on overall QoL.

Relationships between characteristics of individual and other components of the model

Sociodemographic variables

Age

Henderson et al (2012) found that younger PLWHA had significantly better functional status than the older ones. However, several other studies have found that age is not an independent predictor of symptom status, functional status, general health perceptions and overall QoL (Sousa et al 1999). This corresponds to the findings of a cross-sectional study involving 712 PLWHA by Nokes et al (2000) in the USA who found that none of the domains of the Wilson and Cleary model were associated with age. The conflicting results from the small body of evidence that exists may suggest that age has little or no impact on QoL domains. These findings further suggest that other factors such as adherence to ART, HIV biomarkers (CD4+ count, viral load and time since HIV diagnosis), educational status, income etc might have contributed to age not having an independent impact on QoL.

Ethnicity

There is limited evidence about ethnicity, but it was found to be a significant predictor of symptom status (mental summary score), functional status (physical summary score) and general health perceptions (Henderson et al 2012). Henderson et al (2012) dichotomised ethnicity into White and non-White and found White ethnic groups had significantly fewer symptoms, better functional status and better perceived general health. However, this form of ethnic classification may not apply to other parts of the world. For example, Nigeria is a Black nation with over 250 tribal groups (NPC and ICF Macro 2008) thus, ethnic classification is based on a tribal group rather than racial colour.

Education

The quantitative literature presents ambivalent evidence about education. Years of education were not significantly related to the principal Wilson and Cleary model components (biological/physiological factors, symptom status, functional status, general health perceptions, and overall QoL) (Henderson et al 2012). Similarly, Portillo et al (2005), and Nokes et al (2000) found that education was not significantly related to life satisfaction. Contrarily, Phaladze and colleagues (2005) note that fewer years of educational attainment as a measure of characteristics of the individual is associated with poorer life satisfaction as a measure of overall QoL. Adewuya et al (2008) argues that lower educational level is correlated with poorer QoL in physical health and psychological domain.

The findings would suggest that lower educational level has a direct negative impact on QoL domains. This is because studies have found that persons with higher education tend to have better job, earn money, able to seek better health behaviour and adhere to health promotion programmes; these, in turn, could have a profound positive impact on well-being and QoL (Monjok et al 2010, Ferrans et al 2005, Murri et al 2003).

Gender

There is limited evidence about gender. However, Sousa et al (1999) found that gender is not correlated to symptom status, functional status, general health perceptions or overall QoL.

Disclosure, stigmatisation and discrimination

The quantitative literature presents ambivalent evidence about disclosure. Nokes et al (2011) in their survey found a direct effect of fear of HIV disclosure on overall QoL and that this was significantly moderated by age with a direct inverse correlation with older participants self-disclosing their HIV status to fewer people compared to younger ones. This

corresponds to the findings by Phaladze et al (2005) who also found that disclosure of HIV status worry was a strong predictor of the overall QoL. Contrarily, Nokes et al (2000) found that disclosure was not significantly related to life satisfaction as a measure of overall QoL. This disparity may be because the data from Nokes et al (2000) was obtained before the introduction of highly active antiretroviral drugs.

The qualitative literature presents similar evidence about disclosure, stigmatisation and discrimination. Stigmatisation and discrimination are addressed in a number of qualitative studies. Dibb & Kamalesh (2012), Chen et al (2011) and Groft & Robinson (2007) conducted studies in the UK, China and Canada respectively and found that PLWHA were concerned about disclosure of their HIV status; believing that they will be discriminated and stigmatized for their status including the possibility of losing their job. Others are afraid about causing harm to their family, and in these instances, PLWHA may keep their HIV status secret (Chambers et al 2015, Ming et al 2012, Chen et al 2011, Adedimeji et al 2010, Ogbuji & Oke 2010, Geurtsen 2005). The literature reports a number of strategies used to keep HIV status secret. Some PLWHA hide when taking ARV medications (Mutabazi-Mwesigire et al 2015, Chen et al 2011, Ho et al 2010). For instance, a participant in Mutabazi-Mwesigire et al (2015 p.5) remarked that: *"I hide to take my ARVs, I don't want my children to see me taking the drug"*. While other PLWHA remove drug labels and drugs in their underwear box (Park-Wyllie et al 2007). The stigma experienced by the PLWHA affects their QoL negatively and is associated with lack of disclosure of their HIV status (Chen et al 2011). Most PLWHA only disclose their status to trusted family members, priests, or HIV-support groups because of an expectation of support or in return for care (Chen et al 2011, Adedimeji et al 2010, Geurtsen 2005). Because of social stigma and discrimination, some PLWHA decide to seek treatment in centres where they can remain unidentified to avoid disclosure. Often time, the stigma experienced comes from some

family, or health personnel involved in services delivery and this has a particularly detrimental effect on mental health and well-being (Alomepe et al 2016, Ming et al 2012, Ogbuji & Oke 2010, Testa & Lenderking 1999). Below are some testimonies from the reviewed articles:

“I don’t want to let her (my wife) know I have done something wrong and unfaithful to her. It may cause a lot of stress to her. She would question why her husband had done ‘this’ and got ‘such disease’? She might blame herself. Besides, it would be a burden to my children...I would rather kill myself to cover up the disease.” (A participant in Ho et al (2010 p.214)).

“My mother and my sister...rejected me when they knew about my HIV status. They run away from me and stop helping me so that I don’t infect them” (A participant in Ogbuji & Oke (2010 p.132)).

A systematic review by Chambers et al (2015) found PLWHA used several strategies to mitigate the negative effects of HIV-related stigma, which include managing stigma through ARVs adherence and healthcare utilisation. It is reported that stigma has a significant and profound effect in achieving optimum adherence to ARVs because some PLWHA fear that ARV adherence could indicate HIV status (Alomepe et al 2016, Mutabazi-Mwesigire et al 2015, Ming et al 2012, Adedimeji et al 2010). To avoid disclosure and anticipated stigma, some PLWHA tend to compromise adherence (Chambers et al 2015). Chambers and colleagues also found that feelings of shame, blame, fear, and denial were also described as instrumental in delaying health care utilisation among PLWHA. For instance, a mother of an HIV infected child stressed that:

“Because he has the virus, since I gave it to him. If it wasn’t for the virus, he wouldn’t have to take it. And it reminds me every time I make him take the medicine. And I think that reminds him that he has the virus, so it bothers me” (A participant in Chambers et al (2015 p.8))

Other PLWHA chose to decline treatment in order to hide their status (Chambers et al 2015).

“Today we had a very sick lady, and we wanted to give her IV fluids... But she refused to stay here, simply because when she’s being visited, people will know she has HIV.” (A participant in Chambers et al (2015 p.8))

Further, some PLWHA saw that exposing their HIV status may damage the relationship with their loved ones, but others see it as a way to gain acceptance by family members (Adedimeji et al 2010, Ogbuji & Oke 2010). Non-disclosure of HIV status to family and friends due to fear of social isolation and living under pretence especially among females leads many to create alternative stories to explain their symptoms and treatment (Park-Wyllie et al 2007). Due to inadequate knowledge about HIV by family members, friends and community at large, PLWHA suffer social isolation, loneliness and find it difficult to integrate with others. These affect their well-being negatively (Adedimeji et al 2010, Geurtsen 2005). For example, below are testimonies from two studies:

“If my relatives and friends would come here and talk with me I would like it better. I only want happiness with my family” (A participant in Geurtsen (2005 p.45)).

‘My greatest concern is for my two children and the situation has worsened since my illness started. I often have to deny myself food so that my children can eat. I cannot work as hard as before to be able to meet their needs, but I have no choice if I don’t want them to suffer, I need to be strong for them [children]’ (A participant in Adedimeji et al (2010 p.34)).

From the quantitative literature and qualitative literature presented above, it is observed that both strands showed a similar result on the impact of disclosure on the well-being of PLWHA. Therefore, the large body of evidence that exists would suggest that disclosure of HIV status, stigmatisation and discrimination have an impact on HRQoL among PLWHA. This impact impedes on the well-being of PLWHA.

Relationship between characteristics of environment and other components of the model

Social support

The quantitative literature provides evidence about the impact of social support upon PLWHA QoL. Henderson et al (2012) argue that social support has a significant independent influence on symptom status (depression and mental summary score), general health perceptions and overall QoL. Consistently, the qualitative literature suggests that having warm supportive family and friends is essential to good QoL (Alomepe et al 2016, Mutabazi-Mwesigire et al 2014, Ming et al 2012, Ho et al 2010, Groft & Robinson 2007, Barroso & Powell-Cope 2000). PLWHA spoke about the desire for connection with others mainly friends, family members and neighbours. Furthermore, PLWHA reiterated that social support structures help them cope better with the HIV, leading to a sense of fulfilment, satisfaction and hope (Mutabazi-Mwesigire et al 2014, Adedimeji et al 2010). Arguably good social support encourages PLWHA to disclose their disease status and may lead to a reduction in stigmatising and discriminatory attitudes against PLWHA (Chen et al 2011, Adedimeji et al 2010, Geurtsen et al 2005). For instance, some participants stressed that:

“It is important to be surrounded by people who love and care for you” (A participant in Mutabazi-Mwesigire et al (2014 p.4))

“Since I became HIV positive, I have no help from my community. My relatives have abandon me...it has been over a year now and I am unable to go to the hospital and get my monthly blood test and check-up. Other families are very poor and they too are unable to help with money to go to the hospital.” (A participant in Alomepe et al (2016 p.659))

There is also evidence that for some PLWHA loneliness and isolation due to lack of proper social support from their family and friends had affected their well-being negatively. Two participants had this to say:

“If my relatives and friends would come here and talk with me. I would like it better. I only want happiness with my family and this helps you cope with the disease [HIV].” (A participant in Geurtsen et al (2005 p.45))

“Nobody likes me; no one is available to help me...I have no joy.” (A participant in Mutabazi-Mwesigire et al 2014 p.4)

Therefore, the evidence suggests that social support and relationship with family and friends had an impact on the well-being and QoL of PLWHA.

Income

Evidence from the quantitative studies shows that gross annual household income has a significant independent influence on symptom status (depression and mental summary score) and functional status (Henderson et al 2012). Phaladze et al (2005) also found that income was a strong predictor of the overall QoL. Qualitative inquiries have also shown the importance of having a steady income among PLWHA. PLWHA, particularly males, place their career as a high priority because losing a job is associated with a deterioration of their QoL (Ho et al 2010). Also, lack of financial independence among PLWHA plays a negative role on their overall QoL (Alomepe et al 2016, Ming et al 2012, Ogbuji & Oke 2010, Ho et al 2010, Park-Wyllie et al 2007). Ho et al (2010) note that participants considered their work and money as critical elements of QoL and of greater importance than their HIV diagnosis. Some PLWHA prefer having a less demanding job even if it has a lower income to maintain better health (Adedimeji et al 2010, Ogbuji & Oke 2010, Geurtsen 2005). Two participants had this testimony:

“[Good QoL] means staying healthy, having a job, and taking care of myself. The expectation of each person is different. I believe the simplest is the best. Need not

earn a lot but should have sufficient money to cover my basic needs on housing and food” (A participant in Ho et al (2010 p.215-216)).

“I worry about having enough money so that when the disease progresses I’ll be able to afford the medical costs. Then I would feel more at ease and wouldn’t have as much pressure, and I’d even be able to support my family. However, I’m dependent right now on my parents help me to cover the treatment. They are old and tired though, and I don’t want to trouble them any longer” (A participant in Ming et al (2012 p.72))

For some PLWHA the struggle to meet their financial obligations was a concern, and this had a detrimental effect on their QoL. One participant in Alomepe et al (2016 p.659) remarked that:

“Because of my sickness with HIV I am unable to work and pay for my children’s school fees. I used to farm and sell the produce to get money to pay my kid’s school fees. My kids have been sent back from school for lack of school fees and books”

Both quantitative and qualitative literature relating to income show that income has an impact on QoL of PLWHA.

Spirituality/coping

The QoL of PLWHA is affected by how an individual adapts and copes with HIV. A systematic review of qualitative studies by Barroso & Powell-Cope (2000) showed that accepting HIV/AIDS as a chronic disease and maintaining hope for a cure is critical in finding meaning for QoL among PLWHA. While religion provides no cure for HIV, many PLWHA often feel a broad sense of spirituality, and express belief in God or an appreciation for prayer which gives them hope, joy, and helps them to cope with the disease (Dibb & Kamallesh 2012, Adedimeji et al 2010, Ogbuji & Oke 2010, Groft & Robinson 2007, Geurtsen 2005, Barroso & Powell-Cope 2000). Below is a testimony from one of the studies:

“I’m religious, believe in God. Generally, I’ve turned my faith and everything over to God. He’ll take care of me, is really what my belief is, that He kinda takes care of everything. There, it’s an ongoing process, turning things over...Let God worry about what’s going to happen in the future, trust that He will take care of you and things will work out OK” (A participant in Barroso & Powell-Cope (2000 p.342)).

Even though religion gives some PLWHA hope and a means to cope with HIV, for others opprobrium from the religious community may have the opposite effect. For example, one participant has this to say:

“I think the Bible has been misinterpreted by both Blacks and Whites. God is love, but you wouldn’t know it by the way you’ve been treated by these churches if you’re gay... In the Black church, the family preacher might come by to visit, but he wouldn’t want to acknowledge the grief and loss you experience when your lover dies” (Barroso & Powell-Cope (2000: 342)).

For some PLWHA after being diagnosed, they experience a sense of hopelessness, apprehension and have suicidal thoughts (Dibb & Kamalesh 2012, Adedimeji et al 2010, Ogbuji & Oke 2010, Ho et al 2010, Geurtsen 2005, Barroso & Powell-Cope 2000). This is linked to feeling that HIV is an incurable disease, involves being a patient for life, and fear of spreading the virus to others (Ming et al 2012, Ogbuji & Oke 2010, Ho et al 2010, Groft & Robinson 2007, Park-Wyllie et al 2007). Nonetheless, beside these concerns, counselling services offered by health centres and social support from a support group or non-governmental organisation assist participants to adjust and cope with the disease (Alomepe et al 2016, Chambers et al 2015, Ming et al 2012, Adedimeji et al 2010).

Dibb & Kamalesh (2012) argue that some PLWHA see their HIV medication as an important instrument that helps them cope with the disease as it keeps them healthy. Other PLWHA engaged in upward and downward social comparison where they compared themselves with how others cope with HIV. This allowed them to be aware of the

shortcomings of their own behaviour. For example, below are few testimonies from participants in the study of Dibb & Kamalesh (2012:145)

“She told me, [. . .] ‘I’m positive as well’ but she was looking good. I said ‘Oh my God’ Then I knew my life because, if a person like her, looking good as she is, then I should do something and stop moaning about myself, so I stopped”.

“I feel I really cope. I feel I am positive to live with HIV because if I’m not positive I think everything won’t work. And why I am very much positive, the treatment is working. The medication I am taking is working”.

“Sometimes you see people [at the support groups] who are very ill, more than you, and you think ‘Oh, I’m much better off”

The qualitative evidence assessing spirituality/coping shows that spirituality/coping has an impact on QoL among PLWHA in a number of ways.

HIV care services

The qualitative literature suggests that regular medical follow-up for care and medication impacts on the well-being of PLWHA. Regular medical follow-up can be problematic for those with the full-time job due to time constraints and lack of permission from employers to attend regular medical follow up (Ho et al 2010, Ming et al 2010, Barroso & Powell-Cope 2000). One participant from Ming et al’s study from China had this to say:

“...I used to work in Guangdong during the off season. However, because it is inconvenient for me to come back every three months to fetch the medicine, I’ve decided to stay at home [since beginning treatment]” (Ming et al (2010 p.72))

Studies also report that PLWHA show concern about attitudes of health care providers that impact negatively on their QoL. PLWHA note that sometimes physicians do not involve them in decision-making do not provide enough information regarding risks of ARV drugs and do not give enough time to discuss their health issues (Adedimeji et al 2010, Park-

Wyllie et al 2007, Power et al 2003). For example, a participant from Park-Wyllie (2007) study had this to say:

“[The] physician’s attitude was...just let me be the doctor, ...here’s your drugs, go away” (Park-Wyllie et al (2007 p.255)).

Contrary to what is obtained in high-income countries, limitation to access to HIV care and support services for PLWHA resource-limited countries was highlighted as one of the factors affecting the well-being and health of PLWHA (Alomepe et al 2016). Alomepe et al (2016) found that in Cameroon poor infrastructure and limited resources to provide care for PLWHA was found to be affecting their adherence to the ARV and QoL.

“We are supposed to do our follow-up test every 6 months. But they usually charge us for it and many of us cannot afford it. For some of my friends who have money, even if they show up, the machines in the clinic to test our blood may be broken and not working. For many of us, going to private clinic is very expensive and we cannot afford it”. (A participant in Alomepe et al (2016 p.659-660))

However, it is interesting to note that some PLWHA show appreciation of the support from their health care providers (Ho et al 2010, Power et al 2003).

“The doctors and nurses do not treat me differently. There is no discrimination here...They always comfort me and tell me that I look great and my CD4+ count has risen... They improved my quality of life as my self-reliance has been enhanced” (A participant in Ho et al (2010 p.214)).

Therefore, the evidence suggests support services provided in HIV care centres have a profound impact on QoL of PLWHA. This shows the need to intensify the provision of adequate and reasonable quality support services for PLWHA.

Antiretroviral therapy

The qualitative literature about the impact of antiretroviral therapy on QoL is ambivalent. ARVs became widely available from the late 1990s and had a major impact on both the morbidity and mortality of PLWHA. In the qualitative literature, participants view the effect

of ARV drugs on their lives as a promising one as it gives them better health (Herrmann et al 2013, Ho et al 2010, Power et al 2003). Overwhelmingly, PLWHA feel optimistic and hope for the future as they get stronger with medication (Ming et al 2012, Geurtsen 2005, Power et al 2003). Mutabazi-Mwesigire et al (2015) and Adedimeji et al (2010) argue that PLWHA point out that increase in accessibility to ARV drugs has reduced risk of morbidity such as bodily pain, opportunistic infection and improved their physical health and QoL remarkably. For example:

“I’ve been living with this thing for fifteen years, so well I am just grateful every day that I am still alive and I know without these pills I certainly probably would be dead, so it’s striking the balance” (A participant in Power et al (2003 p.139))

“Since I started taking ARVs, I have been fine” (A participant in Mutabazi-Mwesigire et al (2015 p.5))

However, on the other hand, having to take regular medication and having their lives revolving around taking drugs is a major concern for PLWHA (Ming et al 2012, Park-Wyllie et al 2007). As depicted by participants in the study by Park-Wyllie and colleagues (2007), the influence of the ARV regimens on QoL is seen as a ‘trade-off’ between reduced QoL against the increase in long life. This is because side effects can lead to wasting of facial muscles due to body fat redistribution (lipoatrophy and lipodystrophy) and body shape changes because of the drug intake are the major factors for the low self-esteem, stigma, and mental health deterioration and overall well-being (Ming et al 2012, Park-Wyllie et al 2007, Power et al 2003). One participant had this to say:

“I must go back home to take my medicine whenever I am out with friends. It is annoying. If we’re not far from my place, I can go home for the medication. If the place is far from home I bring the drugs with me, but it might be difficult to get water there. I miss doses once every three months or so. It is really inconvenient to go out with friends if I have to remember to take my medicine on time” (A participant in Ming et al (2012 p.72))

Apart from being troubled with the regular taking of the ARVs and the potential side effect of changing body image due to lipodystrophy, other PLWHA struggle with other ARVs side effects such as stomach upset, facial swelling and body weakness. For example, some participants had this to say:

“I look at them making me sick, making me vomit like just want to vomit already just looking at them” (A participant in Herrmann et al (2013 p.5))

“Since I started taking HIV medication I have some bad things happening to my body. The medications make to throw up and it make my face and jaw to swell up to making me look different” (A participant in Alomepe et al (2016 p.659))

The evidence consistently shows that ART has an impact on QoL among PLWHA, even though some of the side effects may detract from QoL.

Summary of main findings from the systematic review of QoL among PLWHA

Following a systematic review of the qualitative and quantitative studies, it is observed that there is commonality or convergence of certain dimensions that explain HRQoL among PLWHA using both methodological approaches. These dimensions include symptom status, functioning, environmental characteristics (family and friends’ relationship, social support/HIV care services, sexual relationship, as well as income/money), individual characteristics (age), psychological/mental distress and general health perception. Data from quantitative studies have shown that reduced biological functioning (low CD4+ counts and high viral load) is associated with poor symptom status; better symptoms status is associated with higher functioning status; worse functioning is associated with reduced perceived general health and subsequently reduced overall QoL in PLWHA. In addition, characteristics of the individual such as gender, age, education, marital status and smoking as well as characteristics of the environment such as income, HIV status disclosure, social and family support impacts on symptoms status, functional status, perceived general health and overall QoL. Overall HIV literature suggests that the Wilson and Cleary conceptual

model is a useful framework for understanding PLWHA QoL and also provides a good fit for the HIV QoL literature. The major limitation is that almost all the evidence is from higher income countries and because of the socioeconomic, cultural, and healthcare differences the results may not apply to a lower-income country. However, the qualitative studies reviewed were conducted in a wide range of high and low-income countries and therefore the findings are more likely to apply to a range of contexts. These show that adaptation/coping with HIV, perceived HIV-related stigmatisation/discrimination, access to antiretroviral therapy/HIV care, spirituality/religious beliefs and social relationships with family and friends impact on QoL of PLWHA.

The literature shows that specific HRQoL dimensions lend themselves to either a qualitative or quantitative investigation. For example, stigmatisation and discrimination, adaptation and coping, spiritual/religious belief as well as life reflection are best explored using a qualitative paradigm. However, the impact of biological functioning, gender, ethnicity and education on QoL is more suited to a quantitative approach. Evidently, it can be argued that complex health phenomenon such as HRQoL is best explained or examined by combining qualitative and quantitative approaches (Ivankova 2013, Ivankova et al 2006). Indeed, by taking advantage of the strengths of each when used in combination, the qualitative and quantitative approaches complement each other and allow for a more robust data collection, analysis and findings (Creswell 2013, Onwuegbuzie & Combs 2011, Johnson et al 2007, Johnson & Onwuegbuzie 2004).

The studies from Nigeria (study setting) obtained from the systematic search are presented in Table 2.6. The summary of the findings and the critique of the studies from Nigeria were presented after the table.

Table 2.6: Summary of the studies from Nigeria that assess HRQoL in HIV

S/No	Author	Location	Population	Method	Findings	Strength	Weakness
1	Akinboro et al (2014)	Southern Nigeria	491	Cross-sectional Study	PLWHA without tuberculosis co-infection and those on antiretroviral therapy reported significantly better QoL in the physical, psychological, level of independence and spirituality domains.	1-Conducted power calculation to estimate sample size. 2-Sample size relative large	1-Used purposive sampling. 2-Used generic QoL instrument (WHOQOL). 3- No rigor in the data analysis (did not adjust result for confounders).
2	Bello & Bello (2013)	Southern Nigeria	160	Cross-sectional study	PLWHA who had received 12 months of ARV therapy showed a significant better overall QoL compared with those who had just begun therapy. Both symptomatic and asymptomatic HIV patients showed poorer social domain.		1-Used purposive sampling. 2-Did not conduct power calculation. 3-Population size relatively small. 4-Used generic QoL instrument (WHOQOL). 5- No rigor in the data analysis (did not adjust result for confounders).
3	Mbada et al (2013)	Southern Nigeria	74 (37 PLWHA (cases) and 37 apparently healthy individual (control))	Case control study	6-minute walk distance, 6-Minute Walk Work and maximum oxygen uptake (VO_{2max}) were significantly lower for PLWH compared with control.	1-Clearly defined cases as stage 1 PLWHA and the control as relatives of the cases and health worker at the research centre. 2-The baseline data i.e age, BMI, height and body weight were similar between the two groups.	1-Did not explicitly mention how the participants were recruited. 2-Did not conduct power calculation. 3-Population size relatively small. 3-Blinding was not clearly mention. 4- No rigor in the data analysis (confounding factors were not accounted for).
4	Folasire et al (2012)	Southern Nigeria	150	Cross-sectional study	Asymptomatic HIV-positive patients had significantly better mean QoL scores than symptomatic patients. Irrespective of stage of HIV status and sex all PLWHA showed lower social domain.	Used random selection technique to recruit participants.	1-Did not conduct power calculation. 2-Population size relatively small. 3-Used generic QoL instrument (WHOQOL-Bref). 4- No rigor in the data analysis (did not adjust results for confounders).

Table 2.6: Summary of the studies from Nigeria that assess HRQoL in HIV...continued

S/no	Author	Location	Population	Type of study	Key findings	Strength	Weakness
5	Odili et al (2011)	Southern Nigeria	103	Cross-sectional study	Asymptomatic PLWHA and those with higher family support significantly had better QoL domains in psychological, social and environment compared with symptomatic PLWHA and those with lower family support. Higher educational level was significantly associated with better QoL.		1-Did not explicitly mention how the participants were recruited. 2-Did not conduct power calculation. 3-Population size relatively small. 4-Used a generic QoL instrument (WHOQOL-BEF) 5-No rigor in the data analysis (did not adjust results for potential confounders).
6	Abasiubong et al (2010)	Southern Nigeria	309	Cross-sectional study	Female PLWHA showed poorer QoL compared to their male counterparts.	1-Used random sampling technique to recruit participants 2-Population size relatively large. 2-Used HIV-specific QoL instrument (HAT-QOL).	1-Did not conduct power calculation. 2- No rigor in the data analysis (did not adjust result for confounders).
7	Fatiregun et al (2009)	North Central Nigeria	252	Cross-sectional study	Symptomatic HIV-positive patients had significantly poorer mean QoL scores than asymptomatic patients	Population size relatively large.	1-Used purposive sampling. 2-Did not conduct power calculation. 3-Used generic QoL instrument (WHOQOL). 4- No rigor in the data analysis (did not adjust result for confounders)
8	Adewuya et al (2008)	Southern Nigeria	87	Cross-sectional study	Poorer QoL in PLWHA was associated with lower educational and poorer social support.		1-Used purposive sampling. 2-Did not conduct power calculation. 3-Population size relatively small. 4-Used generic QoL instrument (WHOQOL). 5- No rigor in the data analysis (did not adjust result for confounders).

Findings and critique of studies from Nigeria

This section examines the studies that have been carried out in Nigeria as this is where this current study is set. In Table 2.6 are the eight studies that aimed to assess HRQoL in PLWHA aged 18 years and older. Except for Bello & Bello (2013) and Fatiregun et al (2009) which were conducted in North-central Nigeria, all the remaining studies were conducted in Southern Nigeria. On a general note, there is a lack of rigour in the data analyses in all the eight studies as they did not adjust results for potential confounding factors such as CD4+ count, viral load, comorbidity, BMI, age, income and education. All of the studies from Nigeria had recognisable methodological flaws, mostly due to issues of study design, recruitment, sample size, and the QoL instrument most of which is to be expected with studies of PLWHA. Apart from the study by Mbada et al (2013) which is a case-control study, the other seven studies (Akinboro et al 2014, Bello & Bello 2013, Folasire et al 2012, Odili et al 2011, Abasiubong et al 2010, Fatiregun et al 2009, Adewuya et al 2008) are cross-sectional studies. The cross-sectional studies were judged to be relatively weak because they provide weaker evidence of causality. One of the reasons for the lack of longitudinal studies to assess HRQoL among PLWHA in Nigeria might be the lack of funding (lack of research grants from either the state or research funding institutions) as this type of study is costly and takes a long time to conduct. Most studies in Nigeria are self-sponsored. Another challenge is that follow up of participants may be difficult because, with exception of cities, most places do not have a defined residential address system and issues around stigma associated with living with HIV in Nigeria.

Mbada et al (2013) conducted a case-control study involving 74 participants to examine physical functioning in people living with HIV/AIDS in Nigeria. They found that there was no significant difference in the physical health component score of PLWHA and the controls. However, PLWHA had a significantly higher mental health component score compared with the control group. Mbada and colleagues did not explicitly mention how participants were

recruited that might indicate risk of selection bias. Also, they used the SF-12 generic questionnaire to assess HRQoL and 6-minute walk distance, 6-minute walk work and maximum oxygen uptake (VO_{2max}) to assess physical functioning. The use of a generic QoL measure by Mbada and colleagues is somewhat appropriate because the study aimed to assess QoL and physical functioning between PLWHA and apparently healthy population. Blinding and follow-up of the participants were not explicitly mentioned, and they adjusted for confounders in their results to determine the net impact of HIV on the QoL and physical functioning of the participants. These above mentioned methodological flaws identified in Mbada et al (2013) study limit the generalisability of their findings. Above all, the case-control study was not an appropriate research design because the outcomes measured were not rare in PLWHA, a cohort study should have been an appropriate research design to assess the outcomes.

Akinboro et al (2014) recruited 491 PLWHA and found that PLWHA with higher CD4+ count had significantly better QoL in the domains of physical and psychological health than those with lower CD4+ counts. Folasire et al (2012) and Odili et al (2011) recruited 150 and 103 participants respectively found that PLWHA with higher social support had a significant better QoL in the domains of psychological health, social relationship and environment. Irrespective of the stage of the HIV infection and gender, PLWHA showed poorer scores in the social domain (Odili et al 2014, Folasire et al 2012, Abasiubong et al 2010, Fatiregun et al 2008). Arguably, the low social domain score may suggest ineffective social support networks, because in Nigeria PLWHA are still exposed to stigmatisation and discrimination (Folasire et al 2014, 2012, Adedimeji et al 2010). The lower scores of women suggest they may be particularly vulnerable in this respect.

Folasire et al (2012) and Abasiubong et al (2010) randomly recruited participants. However, five studies used purposive sampling to recruit their participants (Akinboro et al 2014, Bello &

Bello 2013, Odili et al 2011, Fatiregun et al 2009, Adewuya et al 2008). Therefore, lack of random selection of participants raises the risk of selection bias and a non-representative sample.

Bello & Bello (2013) and Fatiregun et al (2009) recruited 160 and 252 participants respectively; they found that symptomatic HIV-positive patients had significantly poorer mean QoL scores than asymptomatic patients in the physical and psychological domains. A similar finding was reported by several studies in Southern Nigeria (Folasire et al 2012, Odili et al 2011, Adewuya et al 2008). Odili et al (2010) found that PLWHA with no presence of comorbidity (tuberculosis) had significantly better QoL compared to TB/HIV co-infected persons. Consistently, seven of the studies showed that PLWHA in Nigeria had higher physical health domain score (Akinboro et al 2014, Bello & Bello 2013, Folasire et al 2012, Odili et al 2011, Abasiubong et al 2010, Fatiregun et al 2009, Adewuya et al 2008). This may not be a surprise because most of the participants studied were already receiving ART and asymptomatic, and it is well known that efficient uptake of ART is significantly associated with better physical functioning (Henderson et al 2012, Odili et al 2014).

A study involving 306 PLWHA found that female participants had a significant lower QoL compared to male counterparts (Abasiubong et al 2010). In contrast, four studies (Akinboro et al 2014, Folasire et al 2012, Odili et al 2011, Fatiregun et al 2008) found that male and female participants had similar scores in the physical, psychological, environmental and social domains of QoL. Furthermore, Akinboro et al (2014) found that age and marital status were not predictors of QoL.

Abasiubong et al (2010) used HIV-specific QoL instrument (HAT-QOL) that was developed in high-income countries before the development and provision of effective ARV medications to assess the impact of HIV on HRQoL of the participants. Furthermore, HAT-QOL was also

developed in the USA using MSM living with HIV. Because QoL is a subjective phenomenon, socioeconomic and cultural differences and health needs, HAT-QOL may not capture or assess the entire whole QoL of PLWHA in Nigeria. Akinboro et al (2014), Bello & Bello (2013), Folasire et al (2012), Odili et al (2011), Fatiregun et al (2009) and Adewuya et al (2008) used a generic WHOQOL-BREF to assess outcome. However, WHOQOL-BREF instrument is not an HIV-specific questionnaire to capture disease-specific HRQoL and is at risk of providing results not specific to HIV.

Akinboro et al (2014) explicitly mentioned a power calculation to estimate their sample size. However, none of the other studies did. Also, the population sizes of five of the studies from Nigeria were relatively small (Bello & Bello 2013, Mbada et al 2013, Folasire et al 2012, Odili et al 2011, Adewuya et al 2008). Therefore, the lack of a power calculation to estimate true representation of population and the use of small sample size may lead to the study being statistically under-powered their findings, and these may limit the generalisability of their findings.

In Nigeria, it was found that socioeconomic status was significantly associated with QoL of PLWHA. Odili et al (2011) found that PLWHA with higher income significantly had better QoL in the domain of physical health, psychological health, social relationship, environment and spiritual beliefs compared with those with lower income. Similarly, Akinboro et al (2014) and Odili et al (2011) found that PLWHA with higher education (college and university qualifications) significantly had better QoL in the domain of physical health, psychological health, social relationship, environment and spiritual beliefs compared with their counterparts. Currently, the existing empirical findings on HRQoL of PLWHA in Nigeria have focused mainly on determinants of HRQoL. However, the impact of HIV on HRQoL and the association between domains of HRQoL in PLWHA in Nigeria as promoted by the Wilson and Cleary HRQoL model is not known. The impact of characteristics of the individual and

characteristic of the environment on biological functioning is not known. Additionally, the meaning and the interpretation of the associations which emerge from the quantitative studies including the interpretations of the outliers and poorly understood quantitative results are not known.

There are very few studies that examine QoL among PLWHA in Nigeria, and most of the studies are quantitative therefore are not very sensitive to the cultural context. Nigeria is a multicultural state with different sociocultural norms and values across the regions, and all the studies from Nigeria were carried out in Southern or North-central Nigeria which are very different to North-east Nigeria. Therefore, the generalisability of the findings from Southern Nigeria will be limited. Thus, there is a need for a study that is specific to a region that will reflect the sociocultural norm of the region.

Conflict and HIV transmission, adherence to ARVs and QoL

As there was a high level of political instability in the study area during the fieldwork period, this element was added to the study aims. Literature in this area was searched to identify evidence about the impact of conflict on HIV transmission and care. There is an assumption that violence fuels HIV transmission but a comparison of HIV prevalence in populations directly affected by the conflict with those not directly affected in sub-Saharan Africa found insufficient data to support this (Spiegel 2007, Spiegel 2004). Studies commissioned by the AIDS, Security and Conflict Initiative found that the current indices of fragility at country level did not demonstrate any significant association with HIV and that fears of much-elevated HIV rates among soldiers have been overstated (de Waal 2010). The impact of conflict on HIV/AIDS in sub-Saharan Africa is largely unknown but there is concern that, in situations of conflict, the most vulnerable populations, such as women and children, are at increased risk for

HIV through sexual violence, forced occupational exposure and limited access to health care or testing (Mills et al 2006).

Anema et al (2008) conducted a retrospective study aimed to examine the potential influence of conflict on HIV prevalence in 7 sub-Saharan countries (Burundi, Sierra Leone, Rwanda, Democratic Republic of Congo, Liberia, Sudan and Uganda). Anema and colleagues found that widespread rape increased the absolute HIV prevalence of these countries by only 0.023% after controlling for confounding factors such as disease stage, multiple rapes, and presence of sexually transmitted infections. Further, a metaanalysis by Watts et al (2010) aimed to determine the impact of conflict on HIV transmission found that the incidence of HIV infection increased by less than 0.5% in sub Saharan countries affected by conflict.

Recently several international agencies such as the United Nations High Commissioner for Refugees (UNHCR) and the WHO indicated that provision of combination antiretroviral therapy to HIV infected people in emergency settings represents a human rights and public health imperative (Olupot-Olupot et al 2008, UNHCR 2007, WHO 2006). High adherence to ARV has been cited as the most common reason for achieving maximum viral suppression to ensure favourable treatment outcomes (Ramadhani et al 2007, Sethi et al 2003). In a conflict setting, several people are likely to be living as internally displaced persons (Garang et al 2009, Mills et al 2006). However, studies of adherence to ARV treatment and treatment outcomes among displaced populations in conflict settings find levels to be comparable to stable settings (Griffiths & Ford 2013, Mendelsohn et al 2012, Garang et al 2009, Kiboneka et al 2008). However, Olupot-Olupot et al (2008) carried out a qualitative assessment of the impact of conflict and adherence of ARV among PLWHA and found that security issues prevented access to health care facilities, making multiple doses impossible. Olupot-Olupot and colleagues (2008) point out that fear due to witnessing torture, abduction or killing were the

cause of poor adherence to ARVs. For example, some participants in Olupot-Olupot et al (2008 p1883) had this to say:

“The poor security situation results in loss of medical forms, running far away from the clinic and forgetting ARVs in the hurry to escape.”

“Insecurity results in loss of drugs or forgetting to pick them in time from the house. If you hear the alarm, you just take off.”

“Clients fear meeting Karamojong cattle rustlers on the way, and fail to keep appointments or cannot wait in the line at the clinic beyond a certain time.”

Furthermore, Olupot-Olupot et al (2008) found that high cost of transportation, limited health personnel and a limited supply of ARVs were also found to be limiting access to care. For example, some participants had this to say (Olupot-Olupot et al (2008 p.1883):

“Dates for review are sometimes too close, especially when ARVs [antiretroviral] are in short supply or at the initiation stage of the cART. To come back every 2 weeks or every month means many trips to the health unit, which is too expensive to make.”

“Health workers are either very few or not available, and yet you cannot get a refill before being seen by a health worker.”

There is also evidence about the impact that political violence has on QoL. Political violence causes massive destruction of major infrastructure and utilities, resulting in a lack of shelter and energy sources, deterioration of safe water supply and sanitation services, lack of access to healthcare services, food insecurity and overcrowding (Gard et al 2013, Mills et al 2006). Therefore, people may find themselves in a situation of having to flee to safety and become refugees. Refugees are particularly vulnerable to mental ill-health as a result of the trauma experienced before and after migration (Aziz et al 2014, Hammoudeh et al 2013). In general, the relationship between depressive symptoms and lower QoL in PLWHA has been well established in the non-conflict settings (Martin et al 2014, Henderson et al 2012, Rao et al 2012) but little is known about the impact of conflict on HRQoL in PLWHA. Gard et al (2013) conducted a study to examine the association between HIV infection and stressful events on

HRQoL among 936 Rwandan female genocide survivors. After controlling for sociodemographic variables, depression, HIV status, CD4+ count, and genocide related rape, women with high post-traumatic stress symptoms significantly had lower overall QoL than women with fewer post-traumatic stress symptoms. In another multicentre study by Leserman et al (2005), the association between post-traumatic stress symptoms and HQOL was examined among 611 HIV-infected adults in the US. Leserman et al (2005) found post-traumatic stress symptoms. Additionally, with other factors such as the number of lifetime trauma experiences and the number of current stressful events were associated with lower QoL. Therefore, the small body of evidence that exists would suggest that political violence has an impact on HRQoL among PLWHA. It may also impede their access to treatment.

Why is this study needed?

Understanding critical determinants of QoL has implications for the care of PLWHA. Recently, QoL has been incorporated into assessments of quality of service delivery, health outcome (Clayson et al 2006, Higginson & Carr 2001) and cost-effectiveness analysis (Kelley-Gillespie 2009) in both research and clinical practice to inform decision making. In Nigeria, several attempts have been conducted to assess HRQoL among PLWHA (Bello & Bello 2013, Folasire et al 2012, Abasiubong et al 2010, Fatiregun et al 2009, Adewuya et al 2008, Olley & Bolajoko 2008). However, these studies have several methodological flaws noted about them in the above critical appraisal sections which limit the generalisability of their findings.

All the existing empirical findings on HRQoL of PLWHA in Nigeria were predominantly conducted in the Southern part of the country, and the Northern part is understudied. Furthermore, the studies have explicitly focused on determinants of HRQoL with none considering the relationships between the domains of HRQoL as promoted by the Wilson & Cleary model. Also, HRQoL studies in HIV in Nigeria are not extensively studied. None have

used a conceptual model as a theoretical guide. The revised Wilson and Cleary model is the most sophisticated and comprehensive validated tool that gives a better understanding of the pattern of the impact of a particular disease on HRQoL (Sousa & Kwok 2006, Sousa et al 1999, Vallerand et al 1998). It also helps to understand the relationship between the QoL concepts (Wilson & Cleary 1995). Therefore, it is important for the clinicians and policy makers involved in HIV care in Nigeria to focus on evidence-based research that goes beyond identification of factors influencing HRQoL of this population; and also include investigation of relationships between QoL domains with the addition of in-depth qualitative interviews. These will also throw light on how HIV impacts on QoL in the context of Northern Nigeria.

Over two decades several attempts have been made to assess HRQoL among PLWHA using HIV-specific measures (for example: MQOL-HIV, AIDS-HAQ, HAT-QOL, HOPES, FAHI, MOS-HIV, and HIV-SI) which were developed before the development of highly effective ARV drugs (Ahonkhai et al 2012, Duracinsky et al 2012b, Clayson et al 2006). The development these outcome measures were mostly carried out in high-income countries and using English-speaking Caucasian gay men in the US (WHOQOL-HIV Group 2003). Arguably, socio-cultural and semantic disparities in health belief perceived health and value systems might not be accounted for in the development of these existing pre-ARV HIV-specific measures (Duracinsky et al 2012a, 2012b). In 2012, a new HIV-specific HRQoL instrument called PROQOL-HIV was developed during the era of highly active ARV drugs. PROQOL- HIV measures QoL domains such as symptoms (lipodystrophy, sleep and energy/fatigue), functional status (cognitive, physical and ADL), general health perception, coping, financial constraints and health care satisfaction (Duracinsky et al 2012a: see detail of the PROQOL-HIV in Chapter Three under the quantitative survey instruments section on page 117 - 119).

Mixed method research was used to develop the PROQOL-HIV questionnaire (Duracinsky et al 2012a), and subsequently, the impact of HIV-related stigma and physical symptoms on HRQoL among PLWHA used the same cohort from Australia involved in the development of the PROQOL-HIV questionnaire (Herrmann et al 2013). The findings of Herrmann and colleagues, however, may not apply to the Nigerian population because of socioeconomic and cultural differences. Therefore, it is important for the clinicians and researchers involved in HIV care in Nigeria to focus on evidence-based research that goes beyond identification of factors influencing HRQoL of PLWHA and to also include investigation of relationships between QoL domains and examine this with the Nigerian context.

It is a fact that PLWHA are known to have poorer QoL compared to healthy general population (Olupot-Olupot et al 2008). The provision of effective ARVs is vital in improving QoL in PLWHA from the perspective of public health. Several studies have reported that PLWHA receiving ARVs in conflict areas have shown similar clinical outcomes compared to those in stable political settings (Kiboneka et al 2008, Culbert et al 2007). Previous qualitative studies have explored socioeconomic, cultural and structural factors that influence access and adherence to ARVs in limited resource settings (Kiboneka et al 2009 Olupot-Olupot et al 2008). However, none have explored QoL within the context of armed conflict. Therefore, this study will give an additional understanding of the impact of armed conflict on QoL of PLWHA.

It is hoped that this study will provide a comprehensive understanding of HRQoL through the use of a HRQoL conceptual model that provides a holistic understanding of QoL. This will include the use of a recently developed HIV-specific QoL measure and include in-depth interviews with PLWHA to provide insight into their perception of the impact of HIV on QoL from a Nigerian perspective. Understanding HRQoL among PLWHA in North-east Nigeria from their perspective will serve as a foundation to evaluate, identify and promote relevant,

compassionate, and culturally sensitive pragmatic health care. It is hoped that this study will also provide a better understanding of what is culturally and personally important, satisfying, and valuable to PLWHA in Nigeria that will enable policymakers and healthcare professionals in accommodating, negotiating, and restructuring HIV/AIDS care services within the context of their clients' lives. This will add to the emerging body of knowledge on HRQOL among PLWHA in Nigeria.

Aims and objectives

This study will use samples of PLWHA receiving ART in North-eastern Nigeria and adopt a mixed methods research design (qualitative and quantitative) to achieve the following aims:

1. To examine the determinants of HRQoL of PLWHA and to test to see if they fit the revised Wilson and Cleary model.
2. To examine the relationship between the components of the revised Wilson and Cleary conceptual model of HRQoL.
3. To explore whether the lived experience of PLWHA can provide a deeper understanding of how HIV impacts on QoL. The qualitative study will also help to evaluate and interpret results from the principally quantitative study and examine the impact of political conflict on QoL of PLWHA.

The objectives of the study are:

1. Using the revised Wilson and Cleary model to:
 - a. Examine whether biological function has a direct effect on symptom status.
 - b. Examine whether symptom status has a direct effect on functional status.
 - c. Examine whether functional status has a direct effect on general health perception.
 - d. Examine whether general health perception has a direct effect on overall QoL.

- e. Examine whether the characteristics of the individual has a direct effect on biological functions, symptom status, functional status, general health perception and overall QoL.
 - f. Examine whether the characteristics of the environment has a direct effect on biological functions, symptom status, functional status, general health perception and overall QoL.
2. Using the revised Wilson and Cleary model to:
 - a. Examine whether biological function has an indirect effect on functional status, general health perception and overall QoL.
 - b. Examine whether symptom status has an indirect effect on general health perception and overall QoL.
 - c. Examine whether functional status has an indirect effect on overall QoL.
 3. To examine whether the data will fit the revised Wilson and Cleary model.
 4. To explore the meaning of the associations which emerge from the quantitative study and to provide a deeper understanding of the impact of HIV on QoL through in-depth interviews.
 5. To assess the impact of political conflict upon adherence on the QoL of PLWHA.

The next chapter is chapter three. The chapter will provide the detail description of how the study was conducted.

Chapter Three

Methodology

Introduction

The previous chapter provided a systematic review of the existing literature that assessed QoL in PLWHA, the rationale for this study, the relevance of this study, and the aims and objectives of this study. This chapter provides a detailed description of how the study was conducted. Firstly, there is a discussion of the epistemological underpinning and overall research design adopted. Secondly, are details of the methods used defining the study site and population; sample size and sampling technique; instrumentation; study procedure (data collection); ethics; and data analysis and interpretation.

Epistemology

Epistemology is a means of describing, understanding and interpreting “how we know what we know” (Crotty 1998 p.8). It deals with possibilities, scope, nature and the overall basis of acquiring knowledge (Creswell & Plano Clark 2010, Fuller & Loogma 2009, Darlaston-Jones 2007, Green & Thorogood 2006). It clarifies the relationship between what is being sought to be known or already known and the knower to make sure that the knowledge gain is justifiable and rich (Darlaston-Jones 2007, Denzin & Lincoln (2000). For example, it is well documented that HIV infection is a disease that affects both biological and social dimensions (Duracinsky et al 2012a, Folasire et al 2012, Deribew et al 2009). HRQoL is thus linked to both biological and social constructs (Garvie et al 2009, Henderson et al 2008, Sousa & Kwok 2006, Ferrans et al 2005, Phaladze et al 2005, Wilson & Cleary 1995). Biological aspects such as disease stage or symptom severity can be measured, whereas social aspects such as the impact on everyday life are better suited to a more qualitative approach. To ensure that an appropriate epistemological framework underpinned this mixed methods research, both a positivist

epistemology (positivism) and social constructionist epistemology (social constructionism) were adopted as the theoretical framework.

Positivism

Positivism is a widely practised research approach in social and health sciences (Bryman & Bell 2011, Crotty 1998). It underpins how social reality is studied independently of the researcher (Howitt & Cramer 2011, Vanhook 2007, Mertens 2005, Claussen 2004). Positivist epistemology views social life or reality as a measurable construct that can be operationalised into different variables (Creswell 2014, Tuli 2010, Green & Thorogood 2006). From this perspective, QoL can be objectively quantified and viewed with no imposition of value (Bryman & Bell 2011, Tuli 2010, Vanhook 2007, Claussen 2004). This approach is thus well suited for the objective of the current study that relates to examining the relationships proposed by revised Wilson and Cleary directional model of HRQoL between biological functions, symptom status, functional status, general health perceptions, individual characteristics and environmental characteristics and overall QoL among PLWHA in Nigeria. All these components can be measured to a certain extent.

Positivism uses theory to envisage the outcomes of the research regarding hypotheses. In this current study, therefore, predictions were made that enabled the researcher to explain the relationship between variables (O'Leary 2004, Buchanan 1998). The hypotheses were generated from the revised Wilson and Cleary's conceptual model for HRQoL. For example, it was predicted that poor biological function (for example, reduced CD4+ count or having comorbidity) would increase susceptibility and lead to a higher number and severity of symptoms and subsequently poorer overall QoL.

Positivism uses quantitative research technique to collect measures or numerical data through, for instance, analysing existing official statistics or structured interviews and questionnaires with closed-ended questions. In this way, data collection approximates to experimentation for a situation where an experiment is impossible (Creswell 2014, Bryman & Bell 2011). In this approach, numbers are manipulated to represent empirical facts to test theories and hypotheses as well as identifying patterns of relationship between two or more variables. Positivism emphasises the need for research findings to be generalizable and should be able to be replicated elsewhere (Bryman & Bell 2011, Neuman 2011, Buchanan 1998). Therefore, the required population size was estimated through power calculation, and the selected sample was large enough to have 80% statistical power. On account of replication within research, valid and reliable instruments were used to collect data (see Quantitative survey instrument section on page 117 - 119) (Creswell 2014, Burns & Grove 2005, Buchanan 1998) to assess HRQoL of PLWHA in Nigeria. However, because participants were conveniently selected, the samples were not a true representation of the general population of PLWHA in North-east Nigeria.

Social constructionism

Social constructionism is a concept for understanding and interpreting reality based upon the interaction of individuals within society (Sremac et al 2010, Lit & Shek 2007, 2002, Crotty 1998). Social constructionism entails personal stories of how we understand social reality and is therefore well-suited to studying the subjective nature of QoL as it differs from person to person (Duracinsky et al 2012a). Moreover, social constructionists acknowledge that in life more than one account of reality exists (Lock & Strong 2010, Fuller & Loogma 2009, Hibberd 2005).

In social constructionism the social beliefs, actions, values and attitudes which are communicated symbolically in society are based on shared meanings to account for, explain or

describe the understandings of certain phenomena (Creswell 2013, Manson 2008, Wood & Tully 2005). Thus a social constructionism approach will enhance the understanding of the social beliefs, values and norms that influence HRQoL among PLWHA in Nigeria as well as the lived experience of this population.

Arguably, the position we occupy or attain including the situations in which we partake all result from how we interact with one another (Manson 2008, Holstein & Gubrium 2003). In 1982, Hirst & Wolley also adds that "...we learn about ourselves-what we experience, what we call that experience, what we think and feel about that experience-through the ways others respond to and communicate with us. Even the deepest sensations, such as so-called altered states of mind, are social matters" (.p23). Since this study acknowledges that some aspects of HRQoL are subjective and created through human social interaction, a constructionist approach may facilitate an understanding of HRQoL among PLWHA in the local Nigerian context.

Research design and method

Mixed method research (Quantitative -Qualitative Mix)

This study used a mixed methods approach (cross-sectional quantitative research and qualitative inquiry) using explanatory sequential design to test research objectives (Morgan 1998).

It can be argued that complex health phenomenon such as HRQoL cannot be best explained or examined by a single research paradigm (qualitative or quantitative). This further supports the argument by Ivankova (2013) and Ivankova et al (2006) that neither qualitative nor quantitative research approaches are sufficient by themselves to capture the trends and details of a situation. Indeed, by taking advantage of the strengths of each when used in combination, the qualitative and quantitative approaches complement each other and allow for more robust

data collection, analysis and findings (Creswell 2013, Onwuegbuzie & Combs 2011, Johnson et al 2007, Johnson & Onwuegbuzie 2004, Morgan 1998). Therefore, there is a need for the use of mixed methods research to study the concept of HRQoL among PLWHA. To date, only a few studies have used the mixed method to assess HRQoL among PLWHA (see Herrmann et al 2013 Duracinsky et al 2012a).

Therefore, the reasons for the choice of mixed method research are based on the complexity of the numerous factors that influence health outcome such as QoL. It provided the opportunity for a fuller understanding of complex social phenomena and helped to disentangle complex relationships (Creswell & Plano Clark 2010, Tashakkori & Teddlie 2003). For instance, by using qualitative research, it is possible to gather information about a particular topic or construct that is specific to the studied population and to study phenomena in greater depth.

The rich context of lived experiences captured in qualitative inquiry is balanced with the power of numbers and the aim of generalising quantified outcomes (Sosulski & Lawrence 2008, O’Cathain et al 2007). Quantitative research is weak in understanding the context or setting in which HIV affects QoL of the infected persons, which is a strength of qualitative research. Qualitative research is weak because of its difficulty in generalising findings to a larger group, whereas quantitative research does not have this weakness. Also, the use of mixed methods assisted in explaining the causal processes underpinning the associations identified by the quantitative research. Mixed methods study also provided an approach for developing better, more context-specific recommendations on how QoL could be improved.

The adopted mixed method design has provided complementary advantages of qualitative and quantitative methods (Onwuegbuzie & Johnson 2006, Onwuegbuzie & Teddlie 2003, Morgan 1998) using the priority-sequence model as proposed by Morgan (1998). In this study, a sequential mixed method paradigm was adopted (Onwuegbuzie & Teddlie 2006, Onwuegbuzie & Teddlie 2003) and the quantitative approach was the primary method with the qualitative

approach as complementary (Creswell & Plano Clark 2010, Morgan 1998). As for the sequence decision, a quantitative method was first conducted and then followed up with an in-depth qualitative interview (QUANTITATIVE → qualitative).

Explanatory sequential design

An explanatory sequential quantitative (cross-sectional study) → qualitative (QUAN → qual) mixed method research design was adopted for this study (see Figure 3.1). In sequential explanatory design, more weight is assigned to the quantitative data (Hanson et al 2005). The qualitative data are used to supplement quantitative data (Creswell & Plano Clark 2010, Creswell et al 2008, 2003; Hanson et al 2005). The reason for this choice was because the quantitative data and their analysis provided a general understanding of the research problem followed by analysis of the qualitative data to refine and explain those statistical results by exploring respondents' views more in-depth (Ivankova 2013, Johnson et al 2007, Ivankova et al 2006, Creswell 2003, Tashakkori & Teddlie 2003, 1998). The qualitative study was used to evaluate and interpret results from the principally quantitative study. It was also used to help explain any potential outliers (Morgan 1998). Additionally, the reason for the choice of explanatory sequential design was because there is already a reliable, validated and standardised HIV-specific HRQoL questionnaire in existence (PROQOL-HIV see Duracinsky et al 2012b).

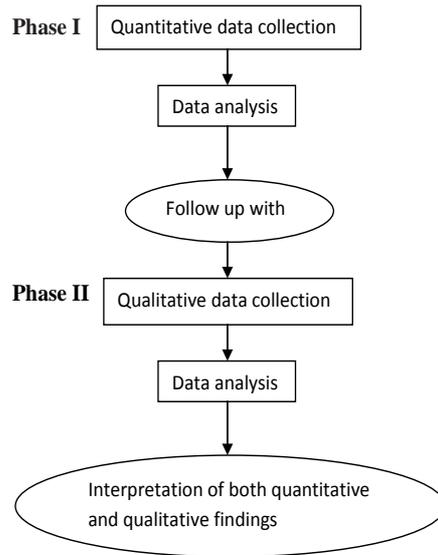


Figure 3.1: Explanatory sequential mixed method research design (Adapted from Creswell & Plano Clark 2011)

Quantitative research design: Cross-sectional survey

A cross-sectional survey with additional data gathered from medical records was used for the quantitative part of this study. This design is suitable to answer the research questions for example What are the factors associated with HRQoL among PLWHA in Nigeria? What are the associations between components of the revised Wilson and Cleary’s conceptual model? A cross-sectional design offers the opportunity for description, comparison, analysis or interpretation of characteristics of a particular population (Bryman 2012, Cohen et al 2011) including associations between two or more variables within a set period. Besides, a cross-sectional study is a cheaper and less time-consuming research design (Cohen et al 2011, Rossi 2010, Blaikie 2009, Carlson & Morrison 2009). As such, considering the short time frame of the study and funding constraints, a cross-sectional study was found to be the most feasible and appropriate design for this study.

Research site and study population

The project site was the HIV clinic at the University of Maiduguri Teaching Hospital (UMTH), Maiduguri, Nigeria. The HIV clinic is coordinated and sponsored by the US President's Emergency Plan for AIDS Relief (PEPFAR) programme. The PEPFAR programme is hosted by UMTH on behalf of the Federal Government of Nigeria in collaboration with Harvard School of Public Health, Boston US to provide services for prevention and control of the spread of HIV in North-eastern Nigeria. UMTH is a 530-bed tertiary health facility spread over 17 wards (Nafada et al 2011). Therefore, the participants of this study were PLWHA receiving HIV-related care at UMTH, Maiduguri, Nigeria.

Inclusion criteria

1. Persons who were 18 years and older and diagnosed with HIV.
2. PLWHA who were attending ARV services in both inpatient and outpatient units of the study centre.
3. Only participants with updated information such as time since HIV diagnosis and recent CD4+ count etc were included in the study.
4. PLWHA who were still engaging with the programme and receiving ARV drugs based on WHO and the Nigerian national guidelines for HIV and AIDS treatment and care in adolescents and adults (WHO/FMoH 2010). These guidelines were detailed in the Introduction Chapter on page 12.

Exclusion criteria

Participants with dementia and disorientation were excluded in the study because answers from these patients will be too untrustworthy (Martin et al 2013, Beuscher & Grando 2009, Hellström et al 2007, Graneheim & Lundman 2004). These groups of excluded participants were identified from their medical history case notes. Moreover, the exclusion of participants with dementia and disorientation was based on the fact that this group of persons may have

difficulty with recall of activities (Tifratene et al 2015, Mograbi et al 2012). For instance, lifetime experience living with HIV infection.

Sequence of the research

Quantitative research

This section provides a detailed description of the sample size and sampling technique as well as recruitment and accessibility, the research instruments, data collection and data analysis of the quantitative survey.

Sample size

Sample size is critical because the true deductions come from it being a representative sample. The ability to detect meaningful differences statistically comes from the right size sample. The ARV programme in the centre where the research was carried out has about 4550 registered PLWHA receiving HIV related health care services at the facility (UMTH). The infinite sample size was determined using the formula below:

$$SS = \frac{z^2 p (1-p)}{d^2} \quad (\text{Bryman \& Cramer 1990})$$

Where SS = minimum sample size required for the study

z = Coefficient of standard normal deviation or z-score (for 80% power usually express as 1.96 at 95% confidence interval)

p = Percentage of population picking a choice (considered for this study as 50%)

d = The acceptable error level (considered for this study to be 5%)

$$\Rightarrow SS = \frac{1.96^2 \times 0.5 (1-0.5)}{0.05^2}$$

Thus, SS = 384.16

The calculation of sample size was based on z-score of 1.96 corresponding to 95% confidence interval and the acceptable error level of 5% (0.05). Bryman & Cramer (1990) recommend

deviation and error levels in health and social sciences research. After the above infinite population size, correction finite population size calculation was used to determine the minimum sample size using the formula below (The Survey System 2012):

$$\text{New SS} = \frac{\text{SS}}{1 + \left(\frac{\text{SS} - 1}{\text{Total population}} \right)}$$

but, total population = 4551 PLWHA

$$\Rightarrow \text{New SS} = \frac{384.16}{1 + \left(\frac{384.16 - 1}{4551} \right)}$$

Thus, New SS = 354.32

In this research, at least 80% response rate was expected. Therefore, an additional number of participants was required to allow for non-response (Fox et al 2009). The final sample size was calculated as follows: New SS/0.8 (Bryman & Cramer 1990). This high percentage of response is likely because previous studies among PLWHA in Nigeria showed similar response rate (Folasire et al 2014, Ezechi et al 2013). Therefore, the sample size at 80% response rate is:

$$= \frac{354.32}{0.8}$$

442.9 \approx 443 persons.

Sampling procedure of the quantitative study

A non-random stratified sampling technique was used to recruit the participants for the quantitative study. During this sampling technique, the HIV clinic manager was initially asked to supply details of all patients who were engaging in the HIV treatment programme. The participants were initially stratified by age and gender because of the disproportionate distribution of HIV infection at the centre where the research was conducted. Fifty-two percent of the PLWHA receiving HIV care at UMTH, Maiduguri North-eastern Nigeria were young

persons aged 18 - 40 years and females constituted nearly 64%. This is similar to the national composition where nearly 60% of PLWHA in Nigeria are young persons aged 15-24 years and female constituting 58% of the HIV infection in Nigeria (FMoH 2011, NACA 2011, WHO/FMoH 2010). Participants were stratified by three age groups: young age (aged 18 - 40 years); middle age (aged 41 - 59 years); and old age (aged 60+ years) as classified by Chang et al (2013).

The sampling frame came from the cohort of PLWHA receiving HIV care at UMTH, Maiduguri since 2002 when the HIV prevention and treatment started in Nigeria. Those who agreed to participate or were selected to participate in the study were checked against the patients'/clients database to ensure they had up to date information and met the inclusion criteria.

Table 3.1 below shows the summary of the total number of eligible participants receiving HIV care at UMTH, Maiduguri. The study centre HIV had a total 4551 registered patients receiving HIV care, and 2905 of these patients were females, and 1646 were males. Among these patients, 2379 (males = 838 and females = 1541) were young age group aged between 18 – 40 years, 2044 (males = 753 and females = 1291) were persons of middle age group aged between 41 – 59 years and 128 (males = 55 and females = 73) of these patients were persons of old age group aged 60 years and older all matched by gender. Therefore, stratification of the participants was conducted in two stages.

Table 3.1: Total number of eligible participants who have up-to-date data were engaging in the antiretroviral clinic at the time of the study

S/NO	Age group	Gender		Total
		Females N	Males N	
1	Young age (18 – 40 years)	1541	838	2379
2	Middle age (41 – 59 years)	1291	753	2044
3	Old age (60 years+)	73	55	128
Total		2905	1646	4551

Stage 1

1. In stage 1, the total participants were stratified into the three age groups namely young age group, middle age group and the old age group and the true representation of each of the age group was determined in three steps:
 - a. First, a total number of all eligible participants was determined.
 - b. Secondly, participants were grouped into the three age groups, and the total number of participants in each group was first determined. In other words, the total number of each stratum was taken in proportion to the size of the stratum.
 - c. Thirdly, after the sample size was determined, each group size was multiplied by the sample size and divided by the total population size (size of entire PLWHA with updated information as described above). Below is the breakdown of the calculation of the sample size of each stratum:
 2. The number of young aged = total number of young aged \times (sample size \div total number of eligible PLWHA enrolled in the ARV programme).
 3. Number of young age participants = $2379 \times 443/4551 = 232$
 4. The number of middle-aged = total number of middle-aged \times (sample size \div total number of eligible PLWHA enrolled in the ARV programme).
 5. Number of middle age participants = $2044 \times 443/4551 = 199$

6. The Number of old aged = total number of old aged \times (sample size \div total number of eligible PLWHA enrolled in the ARV programme).

$$\text{Number of old age participant} = 128 \times 443/4551 = 12$$

Stage 2

Each stratum that is the young age group, middle age group and the old age group were then sub stratified by gender. Therefore, the total number of males and females in each age group was also determined (see table 3.1) and the true representation of each of the substratum (that is, males and females) was determined in three steps in respect to the total number of all eligible participants in each age group:

1. Number of male or female participants in young age group were given by (for example):

Number of males in young age group = total number of males \times (sample size of the age group \div total number of eligible PLWHA in each age group enrolled in the ARV programme).

i. Male participants in young age group = $838 \times 232/2379 = 82$

ii. Female participants in young age group = $1541 \times 232/2379 = 150$

2. Number of male and female participants in middle age group are given by:

i. Male participants in middle age group = $753 \times 199/2044 = 73$

ii. Female participants in middle age group = $1291 \times 199/2044 = 126$

3. Number of male and female participants in old age group are given by:

i. Male participants in old age group = $55 \times 12/128 = 5$

ii. Female participants in old age group = $73 \times 12/128 = 7$

Table 3.2 shows the distribution of the participants in each strata and sub strata of the sample size.

Table 3.2: Distribution of participants by age and gender based on the calculated sample size

S/NO	Age group	Gender		Total
		Females N	Males N	
1	Young age (18 – 40 years)	150	82	232
2	Middle age (41 – 59 years)	126	73	199
3	Old age (60 years+)	7	5	12
Total		283	160	443

Accessibility and recruitment of the participants for the quantitative study

After approval was granted to access to the participants, the researcher met with the potential participants in the reception area of the clinic. The HIV clinic at UMTH, Maiduguri operates five business days per week (Monday – Friday) except on bank holiday. The HIV treatment clinic has a reception area where all patients sit to listen to a ‘health talk’ or wait to be attended by the physicians. At the clinic reception area, the researcher introduced himself, the study, the purpose of the study, how the study will be conducted and also asked the potential participants if they were willing to participate in the study.

After the introductory session, each of the potential participants willing to participate was given an information sheet about the research to read and understand what the study was all about before consenting to participate in the study (see Appendix III). Each information sheet given out was coded with an identification number for easy tracing. This identification number on each information sheet corresponded with the one given on the questionnaire.

Those who agreed to participate in the study were asked to sign the informed written consent form (see appendix IV) before the start of the study. For the inpatients, a similar approach was applied but at the hospital bedside. Each potential participant of the quantitative survey was asked to kindly provide a contact mobile telephone on the socio-demographic data form if they

wished to participate in an in-depth interview at a later date. Participants were told that participation was voluntary with no incentive.

In this research, all eligible participants who consented to participate in the study were recruited into the sampling category to which they belonged until the required number needed for that category was achieved. Any participant willing to participate but was found that their category was full was excluded (twelve and eight participants in the young age group and middle age respectively were excluded).

The non-random stratified sampling of the participants into each stratum was found to be the most suitable because there was a time constraint during the data collection period. Another reason was the environment where the study was conducted which included pronounced social stigma associated with HIV. It was likely to have been difficult to randomly recruit a sufficiently large sample (443 participants) in a relatively short time. The main reasons for this are that not all the eligible participants will agree to participate in the study and the political unrest in the study setting required the completion of data collection as quickly as possible as an attack in and around the study setting might have caused a significant delay in the data collection.

Quantitative survey instruments

The following were used for survey data collection:

1. Socio-demographic form: this form was used to elicit information such as the age, gender, marital status, and formal educational level. Other information such as alcohol use, smoking, and illicit drug use were also retrieved from the socio-demographic form (see Appendix V). This information was used to assess the characteristics of the individual as ascribed by revised Wilson and Cleary HRQoL conceptual model.

2. The CD4+ count, viral loads, and time since diagnosis of HIV/AIDS and any comorbidities were retrieved from the participants' hospital case-note (see Appendix VI). These variables were used to assess biological status of the respondents as described by revised Wilson and Cleary HRQoL conceptual model.

3. The PROQOL-HIV questionnaire (see Appendix VIIA) was obtained and used to measure HRQoL. PROQOL- HIV was developed in France. The advantages PROQOL-HIV have over the previous existing HIV-specific QoL measures are that: 1) it is a multi-sociocultural instrument developed using participants across 9 countries (Australia, Brazil, Cambodia, China, France, India, Senegal, Thailand and the US) ranged from low to high-income settings and across all the continents; 2) it captures issues such as the impact of ARV therapy, sleep disturbance, sexual dysfunction and lipodystrophy that were not addressed by the previous HIV-specific HRQoL measures; 3) it also covers issues associated with experience living with chronic and long term illness unlike the previous ones that were developed when HIV infection was known to be acute fatal disease (Duracinsky et al 2012b).

The questionnaire is a multidimensional HIV-specific HRQoL questionnaire that endeavours to be sensitive to treatment in the era of an effective ART. The questionnaire is a 43-item English version in 11 subscales: general health perception, social relationship, intimate relationship, stigmatisation, emotional distress, health concern, physical and cognitive functioning, spirituality/coping, future, symptoms and treatment. It also includes a further three items: parenthood, financial constraints and health care satisfaction (Duracinsky et al 2012a, 2012b). Each item on the PROQOL-HIV has an answering option from never, rarely, sometimes, often to always. Except for general health perception and health satisfaction, all items are scored on a Likert item scale ranging from 0 to 4 (considering response categories from left to right). Each

sub-scale was expressed as a final score on a 0 – 100 scale with higher values indicating better HRQoL and the composite global score was arrived by averaging these sub-scales score (Herrmann et al 2013). The general health perception and health satisfaction scores were reversed (for instant, 0 = 4, 1 = 3, 2 = 2, 3 = 1, and 4 = 0) before applying scoring rules as guided by the PROQOL-HIV authors. A higher score signifies better functioning and QoL score while a lower score signifies poorer functioning and QoL score. For instance, a higher score for emotional distress indicates lesser emotional distress. The psychometric properties (validity and reliability) of PROQOL-HIV instrument has been detailed by Duracinsky et al (2012b), however, in brief, the intra-class correlation coefficient (ICC) score was of 0.86 score's, and the reliability using Cronbach's alpha was 0.94 and (Herrmann et al 2013, Duracinsky et al 2012b).

4. Interpersonal Support Evaluation List short form (ISEL-SF) (Brookings & Bolton 1988) was obtained to measure social support and the characteristics of the environment of the revised Wilson and Cleary HRQoL conceptual model (see Appendix VIIIA). The Atherosclerosis Risk in Communities (ARIC) developed ISEL-SF instrument to provide a global measure of perceived social support (Payne et al 2012, Emery et al 2004, Brookings & Bolton 1988). The ISEL-SF is a 16-items ordinal questionnaire that contains eight true and eight false questions (Payne et al 2012, Emery et al 2004). Each item on the ISEL-SF has an answering option from definitely false, probably false, probably true to definitely true and each item was scored on a Likert item scale ranging from 0 to 3 (considering response categories from left to right). Total score of the 16 items ranged from 0–48. A score of 0 – 16 signifies low social support; a score of 17 – 32 signifies moderate social support; and a score 33 – 48 signifies high so

5. cial support. The instrument has been validated with high degree of index of internal consistency of Cronbach's alpha value of 0.83, suggesting a high degree of interrelatedness among items (Payne et al 2012).

Data Collection: The quantitative research

Data collection was conducted in English and Hausa language. The Hausa language is a widely spoken language, and it is the universal language of communication after English the official Nigerian language in North-eastern region. Two attending physicians were trained by the researcher before the start of the study. Participants were asked to complete the questionnaire after having read and understood the information provided regarding the research procedure as well as consenting to participate in the study. To have a high rate of questionnaire return, the researcher and the two attending physicians of the HIV care clinic conducted face-to-face interviews for participants who did not understand English or did not want to complete the survey questions independently. For those who did not understand English, the questions and responses were read in Hausa using a translated copy of the questionnaire. The PROQOL-HIV (appendix VIIB) and ISEL SF16 (appendix VIIIB) questionnaire were translated into Hausa by an expert at the Department of Languages and Linguistics of the University of Maiduguri. However, these translated questionnaires were not piloted or validated for adaptation in PLWHA in North-eastern Nigeria before they were used. All this was because of time constraint during the fieldwork.

Furthermore, those participants who wished to be given time to fill in the questionnaire were allowed to take it home with them, and they were encouraged to return the completed questionnaire during their next clinic visit. Participants who did not return their questionnaire were followed-up by contacting them through the provided mobile telephone numbers and encouraged to complete and return the questionnaire.

CD4+ count is the number of CD4 cells measured as a continuous measure per cubic millilitre of human blood. The CD4+ count is measured from 0 – to 1600. In healthy individuals, it ranges from 500 – 1600 cells/mm³. CD4 cells or T-cells is a form of white blood cells that protect a person against all kind infection. Time since HIV diagnosis is time since when PLWHA was first clinically diagnosed with HIV infection. In the current research site, HIV diagnosis was conducted by using an algorithm combining two tests for HIV antibodies. At first, an enzyme-linked immunosorbent assay (ELISA) was used to detect the HIV antibodies and a second test also known as a confirmatory test was conducted using a Western blot method to detect and determine the size of the antigens in the test kit binding to the antibodies. Comorbidity (ies) is the existence of one or more diseases that the participants were suffering from in addition to their primary HIV infection. For example, TB, hepatitis, pneumonia, herpes zoster etc are the common comorbidities in HIV infected persons. The presence of comorbidity of in HIV infected has been shown to have an influence on QoL in PLWHA and has been used as a measure of biological functions elsewhere (Phaladze et al 2005, Portillo et al 2005).

The symptom status, functional status, general health perception and overall QoL components of the model were assessed using PROQOL-HIV instrument. The lipodystrophy and symptom domains of the instrument were used as a measure of the symptom status. The functional status of the model was assessed using the physical and cognitive functioning including intimacy domain of the questionnaire. General health and health concern (worries) domains were used to assess the general health perception while global PROQOL-HIV score and satisfaction with the healthcare of the HRQoL measure were used to assess the overall QoL components of the model.

The demographic factors such as age, gender, marital status, and educational level assessed the characteristics of the individual. Also, the psychological factors such as emotional distress

(affective response), treatment impact and future (cognitive appraisal) of the characteristics of the individual were assessed using PROQOL-HIV questionnaire. However, the characteristics of the environment of the revised Wilson and Cleary model such as social support was assessed using ISEL-SF while finance, spirituality (coping) and social relationships were assessed using PROQOL-HIV instrument (see Figure 3.2 for the summary of how the revised Wilson and Cleary model and PROQOL-HIV instrument was operationalised).

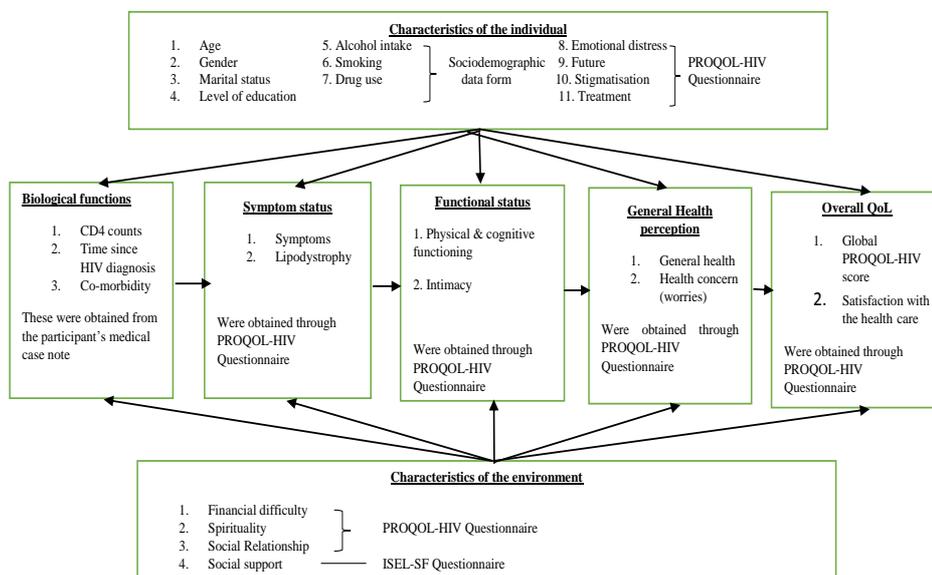


Figure 3.2: Operationalisation of the revised Wilson and Cleary model and PROQOL-HIV

Data management of the quantitative research

The completed PROQOL-HIV questionnaires were scored and summarised according to the author's instructions. All variables in words or phrases were transformed into numbers before making data entry into the IBM SPSS statistical software version 23. Finally, there was a thorough cross-check of all the data entered into the statistical software package by the researcher to minimise error.

Data quality assurance mechanisms of the quantitative research

Data quality assurance is a systematic act of data profiling to uncover irregularities and abnormalities in the data to carry out data cleansing processes such as missing data interruption and outlier removal to enhance the quality of the data. The data were explored to check for missing data and outliers (outlier labelling technique, boxplot and histogram). No missing data was detected. Outlier labelling technique was carried out in three steps. First, the quantile distributions of the variable were determined. Using first (25%) and third quantiles (75%), Tukey factor was determined by $Q' = (Q3 - Q1) g$ (Tukey 1977). Where $Q1$ = first quantile, $Q3$ = third quantile and $g' =$ difference between third and first quantile and $g =$ factor (1.5). Secondly, the extreme values in upper bound and lower bound were detected by extreme upper bound value = $Q3 + Q'$ and the extreme lower value = $Q1 - Q'$. Values above the extreme upper bound and below than the extreme lower bound were labelled as outliers. Outliers were detected in the continuous variables. Thirdly, the outliers were removed by winsorizing. In winsorizing, an outlier is assigned the next highest or lowest value found in the sample that is not an outlier and was done when the number of scores was the legitimate outlier (Tukey 1977).

Data checking

In order to check for missing data, data distribution and test of normality, data exploration was conducted.

Quantitative data analysis

Descriptive statistics

The use of descriptive statistics helped to provide simple summaries about the sample.

1. The following descriptive statistics were used:

- a. Frequency and parentage were used to summarise the socio-demographic characteristics (gender, marital status and educational level) of the participants.
- b. Mean and standard deviation were used to:
 - i. Summarise the sociodemographic variables (for example, age) of the participants.
 - ii. Summarise the sample characteristics (that is, the subscales of the PROQOL-HIV questionnaire and the ISEL-16SF questionnaire) and to test objective 1.

Inferential statistics

1. Before testing objective 1 (a – f) and 2 (a – c) (pages 101 and 102), a preliminary bivariate correlation analysis was conducted to assess the strength and direction of the associations between the QoL domains. Continuous, nominal and ordinal variables were used to assess the QoL domains as appropriate. Therefore, the correlation analysis conducted described below included:
 - i. Pearson's product-moment correlation (r) to assess the relationship between two continuous variables.
 - ii. Spearman's Rho (r_s) to assess the relationship between two ordinal/ranked variables.
2. In order to test objective 1 (a – f) and 2 (a – c) (pages 101 – 102), one-way path analysis (Pedhazur 1997) was used to assess the direct effects on QoL as depicted by the revised Wilson and Cleary conceptual model. Path analysis estimates the magnitude of the associations between variables. These estimates may provide information about underlying causal process. Path coefficients were obtained by employing regression analyses after ensuring that all the regression assumptions were met.

3. In other to test objective 3 (page 102), Structural Equation Modelling (SEM) was used to assess whether the hypothesised revised Wilson and Cleary model held true with the components (biological functions, symptom status, functional status, general health perceptions, and overall including the characteristics of the individual and that of the environment). SEM was also used to test the fit of the revised Wilson and Cleary model of HRQoL to the collected data. It is a comprehensive statistical approach for testing hypotheses about associations between measured and latent variables (Mueller & Hancock 2008, Sousa & Kwok 2006, Sousa & Chen 2002). For example, the latent variables in this study include the components of revised Wilson and Cleary HRQOL conceptual model and measured variables include CD4+ count, time since HIV diagnosis, sociodemographic data, ISEL-SF score and the characteristics assess by PROQOL-HIV.

Primarily, the importance of SEM (vs. other applications of general linear models) was that it provided a description of the associations among latent variables as well as how data fit a particular model or framework in a study that is indicated by multiple measures (Hooper et al 2008, Lei & Wu 2007, Sousa & Kwok 2006, Sousa & Chen 2002). However, the associations in SEM are interpreted similarly to that of regression analysis for each dependent construct (Sousa & Chen 2002). In this study, the criteria for an indication of good model-data fit includes the comparative fit index (CFI), and the root mean square error of approximation (RMSEA) (Hooper et al 2008, Lei & Wu 2007, Sousa & Kwok 2006, Sousa & Chen 2002).

“The CFI provides a measure of complete covariation in the data; RMSEA is a measure of discrepancy between the observed and model implied covariance matrices adjusted for degrees of freedom” (Sousa & Kwok 2006 p.730 - 731). All the indices range from 0.00 to 1.00 (Mueller & Hancock 2008, Sousa & Kwok 2006, Hu & Bentler 1999).

However, for the CFI and RMSEA the value of ≥ 0.90 and ≤ 0.08 respectively were used as a cut-off to indicate a psychometrically acceptable fit (goodness-of-fit) to the data (Blunch 2013, Hooper et al 2008, Lei & Wu 2007, Sousa & Kwok 2006, Hu & Bentler 1999). In RMSEA, the value of 0.05 or less indicated a close fit and less than 0.08 indicated a fair fit (Sousa & Kwok 2006). In SEM chi-square test is sensitive to sample size, it is recommended to report the degrees of freedom, model chi-square value and the other fit indices (Lei & Wu 2007).

4. *p*-values were set at 0.05 for all statistical tests.

IBM SPSS software version 23 was used to conduct the descriptive data analysis and exploratory factor analysis while IBM SPSS AMOS software version 21 was used to conduct the one-way path analysis and the SEM.

Normality tests

Table 3.3 shows the summary of the normality test the QoL subscales. All the subscales were examined for normality using visualisation their histograms, normal distribution curves, Z-scores, skewness and kurtosis. Also, a formal test of Shapiro-Wilk's test and Kolmogorov-Smirnov test were used to test for the normality. The use multiple normality tests were done to compare the various methods as to have a firm basis for transforming the subscales that were not normally distributed (Čisar & Čisar 2010).

Visual inspection of the histograms and normal distribution curves of subscales showed that the examination scores were approximately normally distributed for general health scale, symptoms score and global PROQOL-HIV score subscales, with a skewness of -0.122 (0.116) and a kurtosis of 0.0365 (0.231) for the general health subscale; a skewness of 0.005 (0.116) and a kurtosis -0.059 (0.231) for symptoms score subscale; and a skewness of 0.00023 (0.116) and a kurtosis of -0.036 (0.231) for global PROQOL-HIV score subscale. Also, Shapiro-

Wilk's test (0.036 ($p = 0.200$)) and Kolmogorov-Smirnov test (0.994 ($p = 0.096$)) for global PROQOL-HIV score subscale was not statistically significant. This implies that the global normality assumption of the PROQOL-HIV score subscale is not violated normally. However, Shapiro-Wilk's test and Kolmogorov-Smirnov test for all the remaining subscales were statistically significant, signifying that they were all significantly not normally distributed. The Shapiro-Wilk's test and Kolmogorov-Smirnov test were not considered because they are considered more appropriate for smaller samples, and both tests have a reputation for being oversensitive especially when used in larger sample size (Tabachnick & Fidell 2007). In addition, looking at the Z-scores, skewness statistics and kurtosis statistics of the 13 of 16 of the QoL subscale, the results showed that they were not normally distributed.

Also, a subscale was assumed to be not normally distributed when the skewness statistic and kurtosis statistic of a subscale is more than twice its standard error to determine if the skewness or kurtosis were significant (Čisar & Čisar 2010). Furthermore, for large sample size, a Z-score of ± 2.58 was used to indicate that the distribution is significantly kurtosed or skewed. (Allen & Bennett 2012). A Z-score below -2.58 or above +2.58 indicates that the distribution is significantly kurtosed or skewed. Finally, visual inspection of the histograms, Z-score and SPSS test for skewness and Kurtosis were similar except for the Shapiro-Wilk's test and Kolmogorov-Smirnov test thus; this gave the basis transform the subscales that were not normally distributed.

Table 3.3 Normality test statistics of the variables

Variables	Z-score for skewness (Z_s)	Z-score for kurtosis (Z_k)	Skewness Statistic (SE)	Kurtosis Statistic (SE)	Kolmogorov-Smimov(p-value)	Shapiro-Wilk tests (p-value)
General health	0.01	-0.158	-0.122 (0.116)	0.0365 (0.231)	0.232 (<0.001)*	0.896 (<0.001)*
Symptoms score	0.046	-0.256	0.005 (0.116)	-0.059 (0.231)	0.063 (<0.001)*	0.982 (<0.001)*
Global PROQOL score	-0.002	-0.157	0.00023 (0.116)	-0.036 (0.231)	0.036 (0.200)	0.994 (0.096)
Health concern (worries)	3.71*	-1.44	0.431 (0.116)*	0.168 (0.231)	0.085 (<0.001)*	0.976 (<0.001)*
Lipodystrophy (body change)	0.61	-2.81*	0.071 (0.116)	-0.648 (0.231)*	0.080 (<0.001)*	0.967 (<0.001)*
Physical and cognitive functioning	2.75*	-2.00	0.319 (0.116)*	-0.461(0.231)	0.114 (<0.001)*	0.971 (<0.001)*
Social support	0.98	8.40*	0.114 (0.116)	1.94 (0.231)*	0.096 (<0.001)*	0.963 (<0.001)*
Emotional distress	1.86	-2.93*	0.216 (0.116)	-0.677 (0.231)*	0.099 (<0.001)*	0.966 (<0.001)*
Treatment impact	-5.80*	2.08	-0.673 (0.116)*	0.481 (0.231)*	0.088 (<0.001)*	0.944 (<0.001)*
Intimate relationship	4.84*	-3.03*	0.561 (0.116)*	-0.70 (0.231)*	0.144 (<0.001)*	0.920 (<0.001)*
Stigmatisation	10.83*	6.70*	1.256 (0.116)*	1.548 (0.231)*	0.208 (<0.001)*	0.818 (<0.001)*
Spirituality (coping)	-4.97*	-1.47	-0.576 (0.116)*	-0.339 (0.231)	0.206 (<0.001)*	0.879 (<0.001)*
Financial difficulties	-4.00*	-1.62	-0.464 (0.116)*	-0.373 (0.231)	0.183 (<0.001)*	0.870 (<0.001)*
Future	-8.72*	-0.25	-1.011 (0.116)*	-0.058 (0.231)	0.276 (<0.001)*	0.700 (<0.001)*
Social relationships	-5.06*	-1.65	-0.586 (0.116)*	-0.381 (0.231)	0.204 (<0.001)*	0.879 (<0.001)*
Satisfaction with the healthcare	132.54*	1275.36*	15.375 (0.116)*	294.609 (0.231)*	0.396 (<0.001)*	0.244 (<0.001)*

Note: Z-score for Skewness (Z_s) = Skewness/SE; Z-score for kurtosis (Z_k) = kurtosis/SE;

* data is significantly skewed or kurtoses – therefore not normal: 1). Z-scores below -2.56 or above +2.56 indicates that the distribution is significantly skewed or kurtoses (Allen & Bennett 2012); 2). Statistic is more than twice its standard error to determine if the skewness or kurtosis were significant (Čisar & Čisar 2010). 3). P –values of Shapiro-Wilk’s test and Kolmogorov-Smimov test are < 0.05

Initially, log10 and square root transformation techniques were used to try and normalise the thirteen abnormally distributed subscales, but both techniques worsened the distribution of the data (see Appendix IX). Therefore, a two-step transformation technique was used to try and normalise the data. The two-steps were:

Step 1:

The fractional (percentile) rank of each score was calculated. The fractional rank of the score has values ranging from 0 to 1. The formula for fractional rank is given by:

$$\text{Fractional rank} = 1 - [\text{Rank}(X_i) / n]$$

Where,

$$\text{Rank}(X_i) = \text{rank of value Rank } X_i$$

$$n = \text{sample size}$$

For instance, a participant A has a general health score of 75, which ranks second among 443 participants. Therefore, the fractional rank is $1 - (2/443) = 0.995$. This is interpreted as 99.5% of the sample has a general health score below that of participant A.

Step 2:

An inverse distribution factor was applied to the data:

$$p = \mu + \sqrt{2} \sigma \text{erf}^{-1}(-1 + 2\text{Pr})$$

Where,

$$p = \text{z-score resulting from step 2}$$

$$\mu = \text{mean of } p \text{ (recommendation is 0 for standardised z-scores)}$$

$$\sigma = \text{standard deviation of } p \text{ (recommendation is 1 for standardised z-scores)}$$

$$\text{erf}^{-1} = \text{inverse error function}$$

$$\text{Pr} = \text{probability that is the result of step 1 (Abramowitz \& Stegun 1964)}$$

After the variable transformation, the scales were re-examined for normality. Six scales (health concern/worries, lipodystrophy, physical and cognitive functioning, emotional distress, treatment impact and social support) were reasonably normally distributed. However, seven scales (intimate relationship, stigmatisation, spirituality (coping), financial difficulties, future, social relationship and satisfaction with the healthcare services) after the transformation significantly violated the normality assumption. These seven scales that could not be normalised were dichotomised. Scores range between 0 to 50 were labelled 0 and was termed as low QoL subscale score while all scores greater than 50 were labelled 1 and was termed as high QoL subscale. Table 3.4 shows the summary of the variables transformed using the two-step transformation technique.

Table 3.4 Summary of the variables transformed using the two-steps transformation technique

Variables	No items	Before transformation		After transformation	
		Skewness (SE)	Kurtosis (SE)	Skewness (SE)	Kurtosis (SE)
General health ^a	1	-0.122 (0.116)	0.0365 (0.231)		
Symptoms score ^a	5	0.005 (0.116)	-0.059 (0.231)		
Global PROQOL score ^a	43	0.00023 (0.116)	-0.036 (0.231)		
Health concern (worries) ^b	4	0.431 (0.116)*	0.168 (0.231)	0.103 (0.116)	-0.280 (0.231)
Lipodystrophy (body change) ^b	4	0.071 (0.116)	-0.648 (0.231)*	-0.010 (0.116)	-0.462 (0.231)
Physical and cognitive functioning ^b	4	0.319 (0.116)*	-0.461(0.231)	0.010 (0.116)	-0.300 (0.231)
Social support ^b	16	0.114 (0.116)	1.940 (0.231)*	0.004 (0.116)	-0.155 (0.231)
Emotional distress ^b	4	0.216 (0.116)	-0.677 (0.231)*	0.012 (0.116)	-0.416 (0.231)
Treatment impact ^b	10	-0.673 (0.116)*	0.481 (0.231)*	-0.041 (0.116)	-0.266 (0.231)
Intimate relationship ^c	3	0.561 (0.116)*	-0.700 (0.231)*	0.115 (0.116)	-0.765 (0.231)*
Stigmatisation ^c	2	1.256 (0.116)*	1.548 (0.231)*	0.173 (0.116)	-0.600 (0.231)*
Spirituality (coping) ^c	1	-0.576 (0.116)*	-0.339 (0.231)	-0.330 (0.116)*	-0.656 (0.231)*
Financial difficulties ^c	1	-0.464 (0.116)*	-0.373 (0.231)	-0.360 (0.116)*	-0.564 (0.231)*
Future ^c	1	-1.011 (0.116)*	-0.058 (0.231)	-0.622 (0.116)*	-0.829 (0.231)*
Social relationships ^c	2	-0.586 (0.116)*	-0.381 (0.231)	-0.480 (0.116)*	-0.564 (0.231)*
Satisfaction with the healthcare ^c	1	15.375 (0.116)*	294.609 (0.231)*	-0.850 (0.116)*	-0.548 (0.231)*

Note: * data is significantly skewed or kurtoses that is, statistic is more than twice its standard error to determine if the skewness or kurtosis were significant (Čisar & Čisar 2010); a = normally distributed variables; b = two-steps transformed variables; c = untransformed variables using the the two-steps transformation and they were dichotomised (0 – 50 = 0 and >50 = 1)

Data cleaning and preparation for SEM

The PROQOL-HIV questionnaire subscales with two or more items were parcelled using “a priori questionnaire construction technique” (Little et al 2002 p.166) to form indicator variables before assigning them into their respective seven latent variables of the revised Wilson and Cleary conceptual model. These parcelled indicators of latent variables were then used within the measurement model. For example, emotional distress and treatment impact subscales have four and ten items respectively in the PROQOL-HIV questionnaire. Parcelling refers to an aggregate marker comprised of the sum or the mean of two or more items of a construct (subscale). According to the authors of the PROQOL-HIV questionnaire, the priori guideline for summarising the scores of the items for each subscale is the mean score of the items for each subscale (Durasinsky et al 2012a, 2012b). Therefore, in these analyses the mean is used.

In SEM, parcelling data has several advantages over multiple item data. Parcelled data contain one or more of the following advantages compared to item-level data: higher reliability, higher communality, a larger ratio of common-to-unique factor variance, and a lower likelihood of distributional violations (Little et al 2002). Little and colleagues also advocate for parcelled data because they have fewer estimated variables in defining a construct or latent variable and helps in putting a clean and uncomplicated model compared with multiple item data. However, it is disadvantageous to parcel items if one is dealing with multidimensionality because it can misrepresent the measurement model as it may specify biased loading estimates and make it problematic to interpret the nature of variance of a latent variable (Little et al 2002).

The seven PROQOL-HIV questionnaire subscales that were parcelled and they were individually checked for dimensionality. All the subscales were confirmed to be unidimensional with factor loading ranging from 0.400 to 0.832. In addition, the parcelled subscales demonstrated adequate model fit. Appendix X shows the dimensionality and goodness-of-fit of the parcelled subscales.

Qualitative research design

A qualitative enquiry was used to explore the lived experience for PLWHA including their perception of the way the disease impacts on their HRQoL. The qualitative enquiry was found to be appropriate to achieve a better understanding of the determinants of QoL and the relationship between the domains of the revised Wilson and Cleary HRQoL model that the cross-sectional study elicited. This qualitative design aimed to show some aspects of QoL as experienced in the daily lives of PLWHA in Nigeria.

Inclusion criteria of the qualitative research

1. Persons who participated in the quantitative phase and consented to participate in the qualitative phase.
2. Persons who participated in the quantitative phase who had low, moderate and high overall QoL score that is, global PROQOL-HIV score.
3. Participants who understand and speak basic (Pidgin) English language.

Sampling procedure of the qualitative research phase

A nested purposive sampling technique was used to recruit participants for the qualitative phase of the study. Purposive sampling is a non-probability sampling technique (Bryman 2012, May 2011). Purposive sampling uses the judgement of the researcher in selecting participants to select participants with a specific purpose in mind (Neuman 2011). This sampling technique helped the researcher to select participants that were especially informative about the phenomenon under study (Bryman 2012, May 2011, Neuman 2009). Although purposive sampling is a valuable sampling technique, the selected participants rarely represent the entire population because the researcher does not seek to sample research participants on a random basis (Bryman 2012, May 2011, Neuman 2011, 2009). As such, it holds selection bias because the participants do not have an equal chance for participation (May 2011).

Participants who consented to participate in the quantitative research were also asked if they were willing to take part in an in-depth interview session. Persons who showed interest to participate in the interview were asked to put their mobile telephone number on the

sociodemographic data form for easy communication to arrange an interview. To ensure good representation of each stratum at least two male and female participants were selected among the young age group, the middle age group and the old age group for the interview session. Each stratum included participants with high, moderate and low overall QoL score of the HIV-specific QoL instrument (PROQOL-HIV). Figure 3.3 shows the flowchart of how the participants for the qualitative phase were sampled.

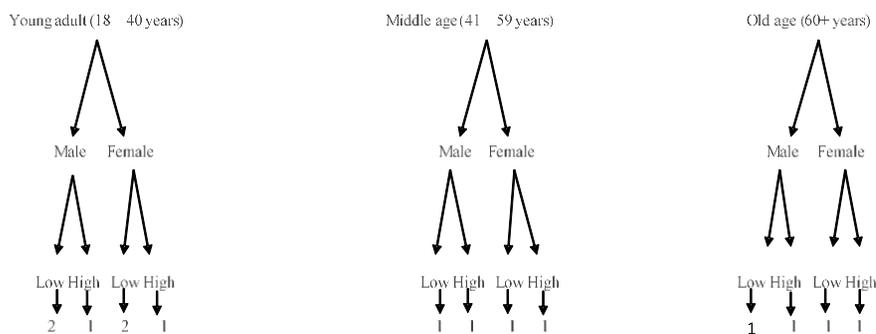


Figure 3.3 Fowchart of the sampling procedure of qualitative participants

Accessibility and recruitment of the participants for the qualitative study

During the quantitative study, participants who consented to participate were asked to provide their mobile telephone number on their quantitative consent form if they wish to take part in the qualitative study. After the quantitative data collection, a total of sixteen participants from the quantitative phase agreed to participate in the qualitative research only fourteen met the inclusion criteria. Two of the sixteen participants were found to be unable to communicate in English or Pidgin. Finally, at least one participant was recruited from each of the twelve strata that were used to recruit the participants of the quantitative phase of the study. Also, each stratum contained at least one or two participants with low, moderate and high PROQOL-HIV scores.

The researcher then identified the corresponding socio-demographic forms of each PROQOL-HIV questionnaire to check for the provided contact mobile telephone number. The potential

participants were initially asked when their next HIV clinic visit was. The researcher met with potential participants at the reception area of the ARV clinic for face-to-face contact.

Qualitative research tools

An in-depth interview was used to obtain the qualitative data. An in-depth interview is suitable for situations where open-ended enquiries are asked to elicit depth of information from relatively few respondents (Rubin & Rubin 2004, Boyce & Neale 2006). The in-depth interview gave the interviewer (the researcher) the opportunity to explore the respondent's perspective or feelings on how HIV infection has affected their QoL. An interview guide was used to collect the qualitative data.

The researcher used a semi-structured interview to collect the qualitative data. The use of a semi-structured interview helped to generate rich and meaningful data because it gave the researcher the opportunity to probe for a more in-depth understanding. It also gave the participants the opportunity to ask for clarification and allowed the participants to steer the direction of the interview at times. It enables participants to talk about QoL using their own words which helped the researcher in developing a real sense of the participants' understanding concept and meaning of QoL and how it was impacted by HIV.

The interview guide (see Appendix XI) helped the researcher to direct the conversations toward the meaning of QoL and the impacts of HIV and political conflict. Also, it served as a prompt to the researcher about issues that needed to be covered to answer the research questions.

Data Collection: The qualitative research

The interview was conducted in both grammatical English and Pidgin. The questions of the interview guide were designed using a simple/plain English language. The grammatical English was used to interview those that were educated while the Pidgin was used to interview participants that were less educated. Because of the social stigma attached to HIV infection, participants may be ashamed to discuss in-depth their lived experience with HIV. Therefore, the interview sessions were conducted in a private environment (consultation room at the HIV clinic). Participants said that they were happy with the interview environment and felt

comfortable during the interview session. Before the interview commenced, participants were given a new information sheet (see Appendix XII) for them to read and understand the qualitative interview session carefully. Also, participants were asked to sign a new consent form and permission to audiotape the interview was also obtained (see Appendix XIII). During the interview, the researcher carefully listened and audio-taped the response of each respondent. Each interview session lasted for 30 minutes or more. All the interviews were conducted by the researcher alone.

Before the start of the interviews nearly half of the participants ask questions for instance, “...hope my name will not appear in any way? “...I believe no photo taking or video recording?” and “...I believe you will only do voice recording as you said before?” The researcher told the participants that was why their names and addresses were not asked, and identification number was given to each participant to help the researcher during data analysis to avoid mix up of the data only the pseudonym will be used in the final text of the thesis. Furthermore, he told the participants that their confidentiality and anonymity would be strictly assured.

There were several perceived preconceptions that may have affected the data collection. PLWHA are a vulnerable group because of the social stigma and health risk associated with the disease. I found it difficult gathering data from these groups of patients; initially, some of these patients were reluctant to participate in the survey. The reasons ranged from not wanting to disclose their identity, wanting to be sure their information would not be divulged and not being able to communicate efficiently in grammatical English language.

Secondly, during the qualitative interview stages some participants specifically the young women were reluctant to speak out or disclose much information about their sexual habits or quality of life. They required lots of encouragement in starting up the discussion. This introduced a range of strategic, ethical and personal issues into the research process. Anytime such behaviour was demonstrated; the researcher used a range of the following responses: 1) ‘We are all adults’; 2) ‘...you know there’s a saying...a problem said, is a problem solved. If no one knows your problem, how can it be solved...’; 3) ‘...and I’m assuring you that your

identity will not be known to anyone, that is why you were not asked to put your name on the consent form. That is why we are doing this interview in this private quiet room in the hospital on a weekend'; and 4) 'No picture will be taken throughout the interview session except the voice recording and nobody will be able to access this apart from those that are involved in the research. Also, all the materials will be destroyed after the research has been completed'. After saying this to the participant, the person generally replied: "*no problem Oga [Sir]...let's continue...*" and finally the respondent became relaxed and started to communicate with ease.

Data management and data quality assurance of the qualitative research

The data were transcribed by the researcher. To compare the accuracy of the data, each transcript was audited by the researcher against the original audio-tape. The auditing assisted the researcher in familiarising himself with the data and ensuring that the transcripts represented what was on the tapes.

Trustworthiness is a term used to ensure confidence in the accuracy and truth of qualitative research findings. Trustworthiness is comparable to reliability and validity use in quantitative paradigm. Lincoln and Guba suggest four criteria for trustworthiness (confirmability, dependability, transferability and credibility) (Lincoln & Guba 1985).

The credibility of the data was achieved in some ways: by the participants' review of their interview transcripts, research assistants' checking for accuracy; and supervisors' review of content to generate themes. The researcher was only able to reach eleven of the fourteen participants and provide them with their corresponding transcribed audio data for them to read and check whether the transcripts were correct. The peer review was done by the researcher, research assistants (HIV clinic physicians) and study supervisors. Initially, the researcher gave the transcripts and audio records to the research assistants to independently review for accuracy before coming back to the UK.

Also, credibility was ensured by building trust with the participants. This was done by ensuring them their identity remained anonymous and confidential and also conducting the research in a

private area. On reflection, perhaps I could have got more in-depth data by asking participants to volunteer for a second qualitative interview to gather additional information which may be stimulated by the process of reviewing the first interview.

Confirmability refers to the similarity between two or more independent persons about the meaning, relevance and accuracy of the findings and is enhanced by involving two or more data analysts. The researcher and the supervisors reviewed, coded the data, compared and discussed discrepancies between coding. There was openness for the creation of new themes when they emerged from the data. Finally, the researcher and study supervisors (who were experienced qualitative researchers and analysts) independently reviewed the transcripts and then compared and discussed differences between transcripts coding and clarification and integration of each of the codes into the appropriate or corresponding emerging themes.

Dependability refers to consistency and whether the study could be repeated. In this current study, this was addressed through keeping a transparent audit of the process of data collection and analysis as well as a thorough description of the decisions during data analysis. On reflection, I perhaps should have summarised the preliminary results of the qualitative study before coming back to the UK. This would have provided an opportunity for an external audit by people who were familiar with the study context to challenge the process of data collection and the findings of the study and could have led to additional data gathering and the development of stronger and better-articulated findings. However, time constraint hindered the researcher's ability to conduct a preliminary data analysis of the qualitative data to conduct the external auditing of the preliminary findings.

A final quality assurance indicator in qualitative research is transferability which is somewhat similar to generalisability or external validity in quantitative research. Transferability refers to the extent to which the findings may be applicable in other contexts with similar populations. To facilitate transferability, the researcher documented a thorough description of the data so that the process was transparent. Also, the researcher provided discussions on how certain field experiences were overcome, for example, the initial reluctant attitude shown by few participants to discuss issues around their sexual behaviour and stigma.

Qualitative data analysis

Framework analysis (Ritchie & Spencer 1994) was employed to analyse the qualitative data. The framework analysis was conducted in five stages: 1) data familiarisation; 2) thematic framework identification; 3) indexing phase; 4) charting process; and 5) mapping and interpretation of data. The transcripts were subsequently imported into the NVivo version 10 qualitative software programme where the verbatim text was catalogued under theme headings called nodes. This software facilitated the exploration of recurring themes and concepts and drew attention to commonalities and variation between the verbatim accounts of the respondents (Herrmann et al 2013).

1. Data familiarisation

Initially, the researcher and the research assistants familiarised themselves with the data through thorough engagement with the data. This included repetitive studying and reading of the transcripts, listening to audio-tapes to have an understanding of the pattern and feel of the data (i.e. the lived experience of the participants).

2. Thematic framework identification

Secondly, critical issues that the participants reported about how living with HIV is affecting their QoL were identified and conceptualised as themes (Ward et al 2013, Srivastava & Thomson 2009, Ritchie & Spencer 1994). The data were reviewed, codes were generated and recorded according to the range of responses to the questions. Recurrent themes that emerged were grouped. These emerging themes were identified by drawing on a priori issues (those informed by the original research aims introduced into interview through the topic guide) (Pope et al 2000, Bryman & Burgess 1994). For example, the initial codes were related to the question schedule for example, 'reaction to diagnosis' (see Appendix XIVA).

3. Indexing Phase

In this stage, a systematic index was applied to the transcribed data with similar meaning in their textual form (Dixon-Woods 2011, Ritchie & Spencer 1994). Index references

developed were marked by different colours. Each colour denoted a specific index (that is meaning) which was linked by a descriptive textual system based directly on the named index headings (Ritchie & Spencer 2004, Ritchie and Lewis 2003). For each passage, the researcher inferred and decided on its meaning both as it stood and in the context of the interview as a whole. Multiple indexing was used to highlight patterns of relationships within the data in a passage that contained a number of different themes that needs to be referenced (Ritchie & Spencer 1994, Bryman & Burgess 1994). In this stage, new themes began to emerge that were not necessarily related to the question schedule and the initial ten codes generated were broken down into seventeen sub-codes (see Appendix XIVB).

4. Charting process

The fourth stage is the charting process. The charts were developed to contain distilled summaries of views and experiences of the participants (Ritchie & Lewis 2003). Those views were rearranged and grouped according to their respective and appropriate emergent themes. Charts were developed with titles and subtitles which were drawn from the thematic framework. The charts were thematically laid out and then drawn up for each key subject areas. Entries were made for the entire participant on each chart. Individual cases were grouped, ordered and linked to the characteristics that were known to have a relevant effect on the patterns of experience. At this stage, the themes moved from being purely descriptive to be more interpretive. For example, the theme of ‘playing with ART’ emerged at this stage. Key themes, such as stigmatisation, were identified and contextualised and others were grouped as they were linked, eg. The ‘important things in life’ was subsumed into ‘HIV is more than being free of disease’. Eight broad themes were generated and following further assessment, consideration and deliberation with my supervisors, six broader themes with five sub-themes finally emerged (see Appendix XIVC).

5. Mapping and interpretation of data

Mapping and interpretation of the data was undertaken to explore the meaning of the associations which emerged from the quantitative study and to provide a deeper

understanding of the impact of HIV on QoL. After all the data was sifted and charted according to core themes, key characteristics of the data were pulled together to map and interpret the whole data set. The charts were reviewed thoroughly, and then the perceptions and experiences of the participants living with HIV were compared and contrasted. This helped to systematically search for patterns and relationships among lived experiences and themes that are either those made explicit by the participants themselves or those derived from implicit connections. For example, for each theme, interpretations of participants views were presented, and differences in the views of the participants were identified. The range of responses expressed by participants helped to provide a deeper understanding of the theme. At this stage, corresponding quotes from the participants were used to illustrate the views being presented. Also, the sample characteristics of the qualitative study were used to interrogate and critique data. For example, whether there were differences between males and females, young and old, wealthy and poor participants.

Merging the quantitative and the qualitative findings (interpretation)

The data interpretation was conducted according to the analytical phases of mixed data analysis outlined by Onwuegbuzie & Combs (2011). These include: 1) data reduction, 2) data display/data transformation, 3) data correlation, 4) data comparison, 5) data consolidation, and 7) data integration of the qualitative and quantitative results. Figure 3.4 shows the summary of the steps that were undertaken for merging and interpreting the quantitative and qualitative data.

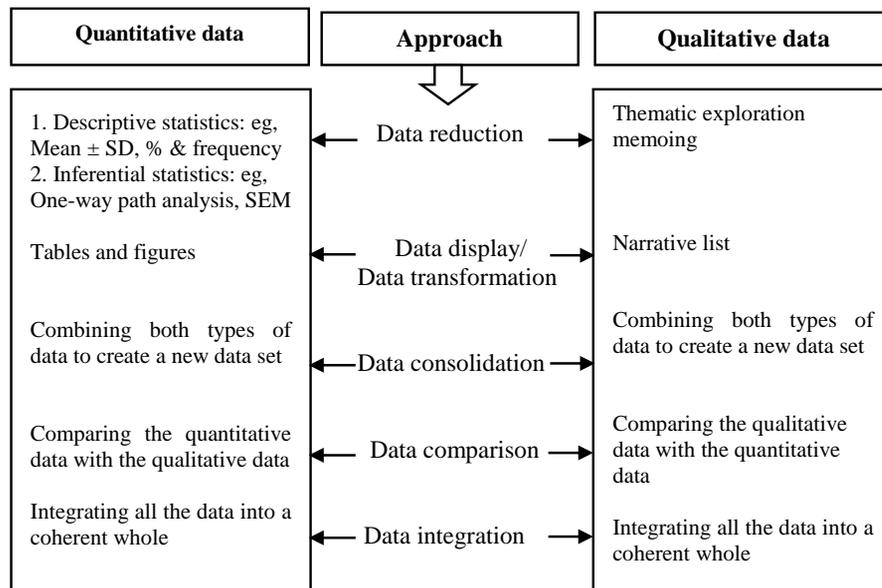


Figure 3.4: Interpretation phases of mixed data analysis (Onwuegbuzie & Combs 2011)

1. Data reduction

All the data collected (quantitative and qualitative) were reduced to more manageable forms as described earlier in the chapter. For example, mean and standard deviation were used to reduce the quantitative data. As for the qualitative data, memoing and thematic exploration were used to reduce the qualitative data while maintaining the context in which the data occurred (Onwuegbuzie & Teddlie 2003).

2. Data display

This stage involved the reduction of information into a suitable and straightforward configuration for easy understanding. Therefore, tables and figures were used to display quantitative data and lists and matrices were used to display qualitative data (Combs & Onwuegbuzie 2010).

3. Data consolidation

In data consolidation stage of the mixed method data analysis both qualitative and quantitative data were combined to create new data sets for possible integration

(Onwuegbuzie & Leech 2006, Onwuegbuzie & Teddlie 2003). In this study, the qualitative data was used to provide a better insight into the relationship found in the quantitative data. For example, when a positive association between physical health and QoL was found, the themes in the qualitative data that helped to explain this and found that it was linked to diminished ability to work, do everyday tasks and to go out and socialise.

4. Data comparison

The quantitative data were compared with qualitative data and vice versa. The reason for data comparison was to assist in finding or establishing a focal point where similarities exist between the quantitative data and qualitative data for possible integration. For example, the quantitative results (that is, the relationships between QoL domains quantitative as postulated by the Wilson and Cleary conceptual model) were compared with any similar themes that emerged from the qualitative data to find whether there are similarities or differences.

5. Data integration

A mixed sequential approach for quantitative and qualitative methods was adopted (quantitative analysis phase was conducted first, which then informs the subsequent qualitative analysis phase) (Combs & Onwuegbuzie 2010, Driscoll et al 2007). At this stage, the quantitative findings were first presented, and the qualitative data was used to provide an in-depth meaning of the quantitative data (see chapter six). For example, the quantitative results found that participants with fewer symptoms and lesser lipodystrophy had significantly better physical and cognitive functioning. This finding corroborates with the qualitative results reported under the sub-themes “impact of HIV on physical functioning” and “impact of HIV on mental well-being and cognitive functioning”. Half of the participants interviewed reported that their HIV related symptoms such as generalised body weakness, easy fatigue and bodily pain were factors affecting the ability to do their routine daily activities such as doing laundry or walking a long distance without being tired and that this negatively affected their QoL. This helped to provide a much more detailed

and nuanced understanding of the HIV impact on QoL whilst also taking account of specific aspects, such as political instability, of the study environment.

Ethical considerations

The ethical approval of the institutional review committee of the University of Essex, UK (see Appendix IIA) and University of Maiduguri Teaching Hospital, Maiduguri, Nigeria (see appendix IIB) were sought and obtained before the commencement of this study. Written informed consent of each participant was sought and obtained in each phase of the study. Additionally, the researcher ensured that the confidentiality and the anonymity of all participants were guaranteed at all times as well by ensuring that all the data was kept securely (Bowling & Ebrahim 2007) by password protecting- and encrypting of the data in the researcher's personal computer. For instance, instead of the use of the participants' name on the consent forms, their antiretroviral clinic identification number was used, and this helped to ensure a high degree of anonymity. Information regarding the purpose, nature and procedure of the study was clearly explained to each participant, and they were given an information sheet to read before they agreed to take part in the study. In the same vein, participants were guaranteed that their participation was voluntary and at any given period they were free to withdraw from the study (Geurtsen 2005). Participants were allowed to ask the researcher any question as a result of reading the information sheet provided before the study began. Furthermore, participants were informed by the researcher if they choose not to participate in the study it will in no way affect the HIV treatment they are currently receiving.

In the qualitative aspect of the study, no identification of data was allowed on the label of the audiotapes or transcriptions of the interviews (Rubin & Rubin 2005). A pseudonym for each respondent was used to identify each of them during write-up (Ming et al 2012). With this, only the researcher had the real name and the identification of the corresponding respondent (Power et al 2003). Access to the transcripts was restricted to the researcher, research assistants and academic supervisors. The research assistants were the physicians involved in the HIV care at the centre where the participants were recruited.

The role of the researcher and development of the study

This section provides a detailed discussion on the role of the researcher during the pre-conceptualisation of the research, data collection and analysis specifically around positionality and reflexivity. Positionality is the notion of how a researcher's values, views, and location in time and space influence how the researcher understands the world (Chavez 2008, Merriam et al 2001, Rose 1997). In this context, gender, race, class, personal experience, profession and other aspects of social identities are indicators of social and spatial positions and are not fixed or given qualities (Hopkin 2007). Arguably, these researcher's identities are markers of relational positions rather than essential qualities. Thus, positionality deals with how these social identities of the researcher (e.g. gender, values, ethnicity/race, culture, and views) may affect qualitative research processes such as recruitment of participants, data collection and data analysis (Vanderbeck 2005). Therefore, there is a need for the acknowledgement of my (the knower's) specific position in any context, because changing contextual and relational factors are crucial for defining identities and my knowledge in any given situation. In this situation, my position may act on the knowledge I have about PLWHA in Maiduguri, the culture, norms and values etc, which may reflect on how I went about recruiting my participant, data collection and analysis to explore the impact of HIV on the QoL of my participants.

Linked to positionality to some extent is reflexivity which refers to a systematic approach of attending to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process (Cohen & Crabtree 2006). In simple terms, reflexivity refers to the researcher's awareness of an analytic focus on his or her relationship to the field of study by which the researcher reflects upon the data collection and analysis and interpretation process (Archer 2012). This is carefully considered in the Discussion chapter.

My clinical background and experience gathered when working with PLWHA in Nigeria for nearly five years before coming to the UK motivated me to undertake this study as described in Chapter 1.

Initially, this study was tilted towards a positivist quantitative paradigm. The initial research questions were: what are the determinants of HRQoL of PLWHA in Maiduguri northeastern

Nigeria? 2). What is the relationship between the emerging determinants and sociodemographic variables such as gender, age, education etc? and 3). What are the relationships between the determinants of QoL and HIV stage such as CD4+ count, time since HIV diagnosis, and viral load? The study proposed using the Medical Outcome Survey for HIV to collect data. After series of meetings with my supervisors, I was given three tasks that is, to read and write reports on: a) the meaning and definition of QoL; b) different approaches of assessing QoL and; c) different HIV-specific QoL measures.

All the works of literature searched were explicit that QoL is a subjective phenomenon, that differs from person to person (influenced by age, gender, educational level, access to basic needs of life –housing and food etc), culture to culture and health status (ill and healthy and even among the ill, it depends on the disease severity). I also conducted a preliminary literature review of quantitative and qualitative studies and found that no single approach was able to capture all the concepts/constructs that defined QoL. At that point, I decided that mixed-methods was the ideal study design.

Further, on searching for theories underlying the HRQoL concept I came across the revised Wilson and Cleary model which hypothesised that HRQoL encompassed biomedical perspective of QoL as well as a social perspective of QoL. According to the model, assessing HRQoL in a population with a chronic illness starts with biological function followed by symptoms followed by how the symptoms affect functioning followed by how functioning affects general health and then how perceived general health influenced overall QoL. The model went further to explain that personal characteristics and environment have a profound effect on biological function, symptom, functioning, general health and overall QoL.

After conducting a thorough literature search on different types of existing HIV-specific HRQoL measures, all of them except PROQOL-HIV measure were developed before the introduction of effective ART, and my study was aimed to assess HRQoL of PLWHA on ART.

These series of reports presented to my supervisors informed my decision to remodel the study design to mixed-methods and to use the revised Wilson and Cleary model and the PROQOL-

HIV questionnaire. Furthermore, my supervisors advised me to include the impact of insecurity on the QoL of the respondents since there was political unrest in the study setting when I was conducting fieldwork.

In 2009, Boko Haram Sects that was founded in 2002 revolted against the Nigerian State with a primary mission to establish an Islamic State in North-eastern Nigeria and oppose the Western style of education. The Nigerian government was able to control the situation within three days. Boko Haram insurgents reorganised and regrouped themselves in 2011 and started attacking soft targets such as civilians in villages, towns, and schools and taking (mainly young) people hostage. Boko Haram insurgents used the young boys and men as child soldiers and young girls and women as wives or slaves. This barbaric behaviour went on and on until in 2012 they started attacking military barracks to obtain arms, custody suites to facilitate prison breaks, and robbed banks to get money. In most states in North-eastern Nigeria (including Borno, Yobe, Adamawa), the federal government declared a state of emergency (The Guardian 2015). Before the declaration of the state of the emergency, most of the local governments in these three states were under the control of the Boko Haram insurgents. For example, twenty of the twenty-seven local governments in Borno were taken over by the Sects (except Maiduguri, Jere, Biu, Hawul, Shani, Bayo and Kwaya Kusar). As the insurgents continued with their inhumane activities, people from the towns and villages moved to Maiduguri for safety as internally displaced persons (IDPs). Across Maiduguri Metropolis various IDP camps were created in schools and newly built housing estates by the Borno state government.

The government declared war against the insurgents by intensifying security personnel deployed to the region and with that the situation started to calm down. After the April 2015 general election in Nigeria, the new government immediately stated its aim to regain back all the territories under Boko Haram by giving more funding, training to the Armed Forces and collaboration with the international community. One month after the change in government these territories were regained, and peace returned to the region. At this point, I began fieldwork to collect the research data in Maiduguri.

The fact that since 2011 Maiduguri has been engulfed with political unrest meant that there was concern from the University of Essex about my safety and the suitability of Maiduguri as a research site. The University advised that the project site should be changed to a place that is relatively safer and the decision was taken to relocate the study to the National Hospital in Abuja, Nigeria. After the researcher reached Abuja and applied for the Ethical Clearance of the National Hospital, the Health Workers Union in Nigeria went on strike and were unable to process the ethics application for the study to go ahead. As time was running out and minimising financial cost, the researcher, therefore, intermitted for a term in the hope that the political situation would calm down. Three months later, the workers in Abuja were still on strike, but the Boko Haram insurgencies in Borno state were much reduced, and Maiduguri was functioning normally. Maiduguri is the home area of the researcher who considered the situation in Maiduguri to be relatively safe, and the hospital was running as usual. The researcher felt that conducting research there would not put him at any additional risk. The study, therefore, took place at UMTM Maiduguri.

Positionality

In 1997, Rose argued that social researchers should recognise their position in research to explore the phenomenon under study and understand their own bias. Positionality is a term used to describe how people are defined, that is “not regarding fixed identities, but by their location within existing networks of relationships which can be analysed and changed” during the research process (Maher & Tetreault 1994 p.164). Positionality is, therefore, the ‘lens’ through which to view the interactions between investigators and the participants (Calabrese Barton 1998). Positionality may include aspects of identity (such as social class, sexuality, gender etc) as well as personal experience of research (such as research training, previous projects worked on) that may influence the interactions between the researcher and the researched (Hopkins 2007). Understanding and mobilising positionality is crucial to efficient data collection and analysis because various identities of the researcher may influence and shape encounters, processes and outcomes of studies (Vanderbeck 2005).

The researcher lived and worked as a health professional previously in the study setting and had multiple identities (as a health worker, researcher, and person of high social class) that could influence the research process. While the methodological approach to the study required the researcher to be an ‘outsider’, the researcher’s familiarity with the study setting made him an ‘insider’. Therefore, in certain circumstances some participants’ saw the researcher as an insider. The insider phenomenon was because of the researcher and society’ commonalities such as language, colour, nationality, familiarity with the study setting and ability to engage in regular conversation in the local dialect (Hausa language) (Hopkins 2007, Merriam et al 2001, Rose 1997).

Additionally, the researcher’s Muslim religious values and beliefs were similar to the majority of the study participants who were Muslims; this made the researcher an insider. The values and beliefs of the Christian minority in the study setting were considered and respected by the researcher as he has some knowledge about Christianity as he has some family members who are Christian. The multi-faith background of the researcher helped him to understand and respect the Christian values of the participants as well as facilitate interaction with them (Gort et al 2002). Also, the researcher himself being from North-eastern Nigeria speaks Hausa fluently with the Northern accent which was shared with participants and used for some of the quantitative interviews. In this sense, they perceived that the researcher was ‘one of our own’.

However, other participants considered the researcher as an outsider because of the researcher’s education, his research role and lack of shared views between the researcher and the participants on issues such as mode of HIV transmission, the impact of HIV health and well-being etc. While the researcher’s knowledge on HIV transmission, living with HIV and the impact of HIV on well-being was mostly informed by the scientific evidence, the participants’ knowledge around HIV infection was from their own experience and influenced by the society’s social and cultural beliefs (Ajayi et al 2013). The societal belief around the HIV transmission in that you cannot get HIV unless you are promiscuous. The societal belief around was discussed further in chapter six.

Also, issues around ethical consideration were strictly adhered to, for instance, confidentiality and anonymity. The researcher was aware that unless these were ensured the participants would be reluctant to participate in the study. Therefore, the researcher tried and gained the confidence of the participants by informing them that their identity will not be disclosed during and after the research and will not appear in any way in the final thesis write-up.

Two participants that participated in the quantitative study were interested in participating in the in-depth qualitative interview. However, the researcher found that these participants did not understand even pidgin English language – as they only speak Hausa therefore; they were not considered for the qualitative study. This means that of the qualitative study was mainly people that were educated at least to some degree. This means that the views of the less educated non-English speakers were not represented in the qualitative results. Although the researcher speaks Hausa, it was not possible to include non-English speakers due to time and financial constraints.

Purposive sampling was used to draw the list of the eligible research subjects for the in-depth interviews. To minimise the selection bias (that is, lack of true representation of the participants), care was taken to select to stratify participants for the qualitative study by gender, age and global PROQOL-HIV score (total of the HIV QoL questionnaire used in the quantitative study). This has helped to capture a balanced view of men and women; young, middle and old age groups; including the views of persons with low QoL, moderate QoL and high QoL score that were obtained quantitatively using the global PROQOL-HIV score.

Importantly, the researcher's skills acquired during his research training at the University of Essex throughout the PhD study especially on how to conduct qualitative research in social and health research was also useful. Positionality and reflexivity' were covered and this knowledge helped the researcher to recognise the influences of social values and norms when conducting the study in his home environment. This training prepared the researcher to move reflexively and appropriately from insider to outsider positions and vice versa during the data.

During the writing-up phase of the thesis, the researcher's positionality was considered at length and discussed with supervisors. This discussion enabled the researcher to achieve increased objectivity and helped to analyse the data in increasing depth towards the end of the research process.

Also, owing to the researcher's familiarity with the environment where the study was conducted, some participants were concerned that the researcher was asking them to explain obvious things. For instance, asking the participants "what it is like living with HIV"; and "do you feel HIV has an impact on your life". Some of the responses began with phrases like: "*As you already know...*", "*It's devastating living with HIV...*" were common. This limited their contribution to the issues being discussed. Nevertheless, the researcher used different methods to encourage participants to open up. For instance, questions like *in what way does HIV impact on your life... or what aspects of your life are affected by HIV then followed by more prompt examples such as family life, work, income, daily activities, physical and mental well-being, sexual behaviour and anything else you can think of that are of interest to you...* were used. Additionally, in the entire interview sessions the researcher began the interview with a disclaimer like – *I know you will feel like I know some of the things I will be asking you. But let's discuss it as if you are telling somebody who doesn't know anything about the issues in this area.* This disclaimer encouraged the participants to give in-depth information about the issues being discussed (DeLyser 2001).

Furthermore, despite being a Nigerian living in Maiduguri and a health professional who had worked before in the study setting, characteristics that could make the researcher an insider, he was considered mainly as an outsider because he did not introduce himself as an insider. The researcher introduced himself as a research student (see Appendix XII). He dressed casually wearing jeans and T-shirt to downplay his identity as a health professional, and the interviews were conducted in private office within the study setting far away from the HIV care centre of the hospital. The participants were allowed to choose a date and time to conduct the in-depth interview. In this case, ten of the fourteen participants chose a weekend in the morning. The participants knew that at this time the study setting (hospital) was quiet with few people around.

Although the researcher downplayed his identity as a health professional, participants' expectations of the benefits the study would bring to the society raised a concern. For example, three participants stated: "*May be this will help to make the government to continue to give us HIV medicine free because we have heard that the foreign funding has stopped*" (Participant P2, P11 and P14). Nevertheless, the researcher kept on informing and reminding the participants of the primary use of the data collected and not to expect immediate changes.

The next chapter is chapter four. The chapter provides the quantitative findings of the study.

Chapter Four

Results of the quantitative study

Introduction

The previous chapter provided a detailed description of how the study was conducted. This chapter provides the results of the quantitative phase of the study. In brief, a cross-sectional survey with additional information from medical records was used with a sample stratified by age and gender based on a sample size calculation. The participants provided socio-demographic information, completed the PROQOL-HIV and ISEL-16 SF questionnaires, and biological function data (CD4+ count, time since HIV diagnosis and comorbidity) were obtained from the participants' medical notes. The response rate was 100% resulting in a sample size of 443.

Descriptive statistics were used to summarise the sample characteristics. A one-way path analysis was used to test the direct effects as hypothesised by the revised Wilson and Cleary conceptual model. SEM was used to assess the model fit of the revised Wilson and Cleary model. EFA was used to identify the factor structure for the PROQOL-HIV questionnaire, and CFA was used to assess the model fit of the reduced factor structure of the PROQOL-HIV questionnaire. Cronbach's alpha was used to assess the internal consistency of the PROQOL-HIV questionnaire before SEM was used to assess the model fit of the revised Wilson and Cleary conceptual model. Before the analyses, normality tests were conducted and some data transformed.

With cross-sectional data, the one-way path analysis and SEM can only measure associations, but 'direct effect' and 'indirect effect' are the common statistical terminologies to use in one-way path analysis and SEM. The terminology should not be taken to imply causal effects. The hypothesised causal relationships between the various HRQoL domains are depicted by the revised Wilson and Cleary model but cannot be statistically ascertained due to the cross-sectional nature of the study design. SEM is not capable of predicting the direction of relationships when used in cross-sectional studies even though it generates a directional model. According to Arnold et al (2005) except when the study is conducted prospectively, it is

difficult to attest whether the different health variables in the model follow each other chronologically.

Sample characteristics

Table 4.1 shows the summary of the socio-demographic characteristics and clinical information of the 443 PLWHA participants. Just over half of the participants (N= 232, 52.4%) were in the young age group (19 – 40 years), 199 (44.9%) were in the middle-aged group (41 – 59 years) and 12 (2.7%) were in the older age group (60 years and older). The majority of the participants were female (N= 282, 63.7%). More than half 244 (55.1%) of the participants were married, and 300 (67.7) had primary school/secondary education. The majority of the participants reported having not currently smoked tobacco (394; 88.9%), not currently consumed alcohol (417; 94.1%) and not currently used an illicit drug (439; 99.1%) during the time of the survey. Participants were only asked whether they currently smoke tobacco, use alcohol or uses illicit drug at the time of the study. Whether any of these substances were previously used but currently stopped at the time of the study was not asked as these behaviours were not common. The participants had a mean CD4+ count of 410.44 cells/mm³ and the mean time since HIV diagnosis was 5.66 years. Fewer than third of the participants had one or more forms of HIV related comorbidity 137 (28.7%).

Table 4.1: Characteristics and clinical information of the sample (N= 443)

Variables	Range	n (%)	mean ± SD
Age (years)	19 – 70		40.74 ± 9.11
Age group (years)			
18 – 40		232 (52.4)	
41 – 59		199 (44.9)	
60+		12 (2.7)	
Gender			
Male		161 (36.3)	
Female		282 (63.7)	
Marital Status			
Married		244 (55.1)	
Not married		199 (44.9)	
Educational Level			
Primary/secondary school		300 (67.7)	
College/university		143 (32.3)	
Currently smokes tobacco			
No		394 (88.9)	
Yes		49 (11.1)	
Currently consumes alcohol			
No		417 (94.1)	
Yes		26 (5.9)	
Current illicit drug user			
No		439 (99.1)	
Yes		4 (0.9)	
Comorbidity			
No comorbidity		316 (71.3)	
Presence of comorbidity (ies)		137 (28.7)	
CD 4 counts (cells/mm ³)	45 – 1580		410.46 ± 55.30
Time since HIV diagnosis (years)	0.8 – 16		5.66 ± 3.40

Note: SD = standard deviation

Further descriptive statistics are presented in Table 4.2. Sixteen QoL subscales were measured using the PROQOL-HIV and ISEL-SF16 questionnaires. In the methodology chapter of the quantitative phase of the study, a test for normality of the raw data of the QoL subscales was conducted and only three subscales, namely general health, symptoms score and the PROQOL-HIV score, were normally distributed. Six subscales were transformed (lipodystrophy, physical and cognitive functioning, health concern/worries, emotional distress, social and treatment impact) and they all assumed normality. Seven subscales (social relationships, intimate relationships, stigmatisation, spirituality, future, satisfaction with the healthcare and financial difficulty) could not be transformed. Consequently, they were dichotomised. Because these subscales were measured on a scale of 0 – 100, scores ranged between 0 – 50 were labelled 0 and those scores greater than 50 were labelled 1. The scores of the subscales in bold were the ones used in the subsequent analysis that is, the preliminary one-way path analysis and structural equation modelling to answer the research objectives.

Table 4.3 shows the Cronbach's alpha value of the PROQOL-HIV questionnaire subscales. An alpha value of the subscales with only one item was not included (general health, future, financial difficulty, spirituality/coping and satisfaction with the healthcare services). The result shows that the alpha values were above 0.8 except for stigmatisation (0.713) and health concern (0.704). Further, the internal consistency of the whole 43-item PROQOL-HIV instrument was a Cronbach's alpha = 0.953 and of the SEL-16 SF was a Cronbach's alpha = 0.891.

Table 4.2: Sample characteristics of the participants (N = 443)

Subscales	Raw			Transformed			Dichotomised %	
	Mean ± SD	Skewness	Kurtosis	Mean ± SD	Skewness	Kurtosis	Low	High
1. General health ^a	50.23 ± 23.06	0.010	-0.158					
2. Symptoms score ^a	46.99 ± 24.07	0.041	-0.256					
3. Global PROQOL-HIV score ^a	56.42 ± 14.65	-0.002	-0.157					
4. Lipodystrophy ^b	51.20 ± 27.27	0.61	-2.81*	51.30 ± 26.16	-0.010	-0.585		
5. Physical and Cognitive functioning ^b	47.66 ± 24.13	2.75*	-2.00	47.80 ± 23.66	0.019	-0.306		
6. Health concern/worries ^b	38.94 ± 19.97	1.19	-4.21*	39.20 ± 19.38	0.102	-0.228		
7. Emotional distress ^b	53.44 ± 27.39	1.86	-2.93*	51.47 ± 25.05	0.016	-0.568		
8. Treatment impact ^b	78.05 ± 14.91	-5.80*	2.08	78.09 ± 14.68	-0.035	-0.249		
9. Social support ^b	27.65 ± 5.16	0.98	8.40*	27.66 ± 5.05	-0.004	-0.163		
10. Social relationship ^c	73.84 ± 24.09	-5.06*	-1.65		-2.80*	-1.01*	27.1	72.9
11. Intimate relationship ^c	39.08 ± 30.58	4.84*	-3.03*		3.12*	-2.80*	70.7	29.3
12. Stigmatisation ^c	18.88 ± 21.48	10.83*	6.70*		5.60*	2.621*	95.9	4.1
13. Spirituality ^c	67.62 ± 27.53	-4.97*	-1.47		-3.32*	-0.663*	40.0	60.0
14. Future ^c	73.98 ± 31.27	-8.72*	-0.25		-3.63*	-0.60*	30.7	69.3
15. Satisfaction with the healthcare services ^c	85.11 ± 46.81	132.54*	1275.61*		12.10*	6.39*	12.4	87.6
16. Financial difficulties ^c	69.69 ± 25.50	-4.00*	-1.62		-3.02*	-0.97	40.0	60.0

Note: * data is significantly skewed or kurtoses that is, z-score for Skewness (Z_s) Z-score for kurtosis (Z_k) is below -2.56 or above +2.56 (Allen & Bennett 2012). The scores in bold are the score to be used in the subsequent analysis. Superscript a = untransformed variables; b = two-steps transformed variables; c = dichotomised variables (0 – 50 = 0 and >50)

Table 4.3: Cronbach's alpha values of the PROQOL-HIV questionnaire subscales (N = 443)

Subscales	No. of items	Alpha value (α)
Physical and cognitive functioning	4	0.843
Symptoms score	5	0.828
Lipodystrophy	4	0.849
Social relationships	2	0.902
Intimate relationships	3	0.874
Stigmatisation	2	0.713
Emotional distress	4	0.926
Health concern	4	0.704
Treatment impact	10	0.806

Bivariate correlation analysis

This section provides a preliminary analysis to assess the strength and direction of the linear relationship/association between the twenty-six variables used to assess QoL before proceeding to assess the research objectives 1 (a – f) and 2 (a – c). A bivariate correlation analysis (Pearson's for continuous, Spearman's Rho for ordinal and Cramer's *V* test for categorical variables) was used to assess the strength and direction of the association between two variables. The correlation matrix is presented in table 4.4. Overall the correlations ranged from -0.179 to 0.741 (that is, weak to strong correlation). For example, there is a strong positive correlation between lipodystrophy and physical and cognitive functioning ($r = 0.68$, $p < 0.001$); between symptoms score and overall QoL measured by global PROQOL-HIV score ($r_s = 0.962$, $p < 0.001$). Lipodystrophy was moderately and positively correlated to health concern/worries ($r = 0.42$, $p < 0.001$). Symptom score was moderately and positively correlated to health concern/worries ($r_s = 0.49$, $p < 0.001$). Also, there was a positive moderate correlation between intimate relationship and emotional distress ($r_s = 0.49$, $p < 0.001$). Similarly, the Cramer's *V* tests showed that there were statistically significant moderate correlations between comorbidity and gender ($\phi = 0.291$, $p = 0.003$), smoking behaviour ($\phi = 0.347$, $p = 0.001$) and alcohol use ($\phi = 0.350$, $p < 0.004$). The correlation analysis also found that there was a weak positive but significant correlation between CD4+ counts and time since diagnosis ($r = 0.35$, $p < 0.001$), lipodystrophy ($r_s = 0.19$, $p < 0.001$), symptoms score ($r_s = 0.15$, $p = 0.002$), physical and

cognitive functioning ($r_s = 0.17$, $p < 0.001$), intimate relationship ($r_s = 0.16$, $p = 0.001$), general health ($r_s = 0.23$, $p < 0.001$), health concern/worries ($r_s = 0.11$, $p = 0.023$) and global PROQOL-HIV score as a measure of overall QoL ($r_s = 0.22$, $p < 0.001$).

Table 4.4 Correlations matrix among measures of variables of the Model (N = 443)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	
Biol funct																										
1. CD4	1																									
2. TSD	<u>.350†</u>	1																								
3. CM	-.080	.062	1																							
Sympstat																										
4. Lipody	.189†	-.037	-.144†	1																						
5. Symp	.149†	.006	-.181†	.722†	1																					
Funcstat																										
6. PCF	.173†	-.039	.205†	.681†	.940†	1																				
7. Intim	.159†	-.024	-.387†	.630†	.592†	.653†	1																			
GHP																										
8. GH	.225†	-.002	-.143†	.786††	.867†	.738†	.551†	1																		
9. HC	.108*	.045	-.165†	.423†	.492†	.509†	.426†	.430†	1																	
QoL																										
10. SwHC	.003	-.021	-.117*	.343†	.286†	.299†	.258†	.233†	.275†	1																
11. GPS	.223†	.037	-.167†	.989†	.962†	.989†	.852†	.918†	.758†	.565†	1															
C o Indiv																										
12. Age	-.042	<u>.306†</u>	.161†	-.056	-.013	-.093	-.044	-.037	-.006	.020	.050	1														
13. Sex	.25*	.070	.291*	.113*	.064	.076	.114	.080	.016	.378†	.131†	-.096*	1													
14. MS	.052	-.023	.273†	-.074	-.088	-.124*	-.380†	-.079	-.086	.141	-.098*	-.065		1												
15. EduL	-.017	.104*	.244	.075	.154†	.104*	.182	.186†	.082	-.281*	.053	.010			1											
16. SmokB	-.142†	-.042	.347†	-.086	-.078	.121*	-.319*	-.049	-.091	-.365†	-.147†	.042				1										
17. AI	-.114*	-.001	.350†	-.094*	-.075	-.113*	-.306*	-.104*	-.098*	-.176	-.150†	-.020					1									
18. IDU	-.055	-.021	.111	-.053	-.061	-.068	-.044	-.018	-.004	-.082	-.063	-.009						1								
19. ED	.065	.083	-.061	.555†	.620†	.517†	.491†	.531†	.543†	.317†	.840†	.122*	.003	-.044	.067	-.044	-.051	-.053	1							
20. Future	.114*	.080	.183	.165*	.164†	.168†	.306†	.207†	.237†	.290†	.461†	.348†	.345†	-.157	-.261*	-.161	.065	-.191	.266†	1						
21. TI	.232†	.129†	-.069	.333†	.300†	.337†	.267†	.376†	.414†	.335†	.575†	.144†	.372†	.118	-.119	-.166	-.304†	-.116	.324†	.271†	1					
Co Envir																										
22. SR	.129†	.053	-.156†	.631†	.571†	.572†	.571†	.483†	.505†	.405†	.953†	.039	.274*	-.121	.103	-.313†	-.152†	.151	.494†	.267†	.387†	1				
23. SS	.019	.016	.020	-.056	-.029	-.099*	-.163†	.007	-.084	-.029	-.095*	.088	.058	.341†	-.040	-.030	.013	.060	-.077	.033	.039	-.062	1			
24. Stigm	.082	.006	-.270*	.308†	.397†	.417†	.480†	.329†	.418†	.381†	.557†	.039	.177	-.190	.046	-.248*	-.111*	-.163	.372†	.161†	.275†	.398†	-.103*	1		
25. SC	.089	-.020	-.272*	.107*	.067	.101*	.175	.048	.146†	.412†	.306†	-.019	.329†	.370†	-.319†	-.312†	-.270†	-.129	.062	.186†	.128†	.234†	.075	-.009	1	
26. Fin diff	.143†	.020	.186	.464†	.363†	.379†	.364†	.424†	.338†	.379†	.730†	.045	.166	-.174	-.101	-.052	-.183	-.168	.392†	.317†	.377†	.482†	.119*	.339†	.280†	

Note: Biol funct = Biological functions; CD4 = CD4 counts; TSD = Time since HIV diagnosis; Sympstat = Symptom status; PCF = physical and cognitive functioning; Intim = Intimacy; GHP = General health perception; GH = General health; HC = health concern/worries; SwHC = satisfaction with healthcare; GPS = Global PROQOL-HIV score; C o Indiv = Characteristics of the Individual; MS = Marital status; EduL = Educational level; SmokB = Smoking behaviour; AI = Alcohol intake; IDU = Illicit drug use; ED = Emotional distress; TI = Treatment impact; C o Envir = Characteristics of the environment; SR = Social relationship; SS = Social support; Stigm = Stigmatisation; SC = Spirituality/coping; and Fin diff = Financial difficulty.

1. Pearson's moment-product (r) was used for continuous variables (underlined and bold)
 2. Spearman's Rho (r_s) was used for categorical (ordinal) variables
 3. Cramer's V (φ) was used for nominal variables (result in bold)
- *= p < 0.05; † = p < 0.01

One-way path analysis

The one-way path analysis was used to provide an estimate of the magnitude and significance of the associations between variables that measured the different QoL domains of the revised Wilson and Cleary model. The analysis helped to examine the relationships in the direction proposed by the model (see Figure 4.1). One-way path analysis was conducted to assess the research objectives (1a – 1f and 2a – 2c). Objectives 1a – 1f: To examine the direct effect that exists between components of the revised Wilson and Cleary model while objectives 2a – 2c was to examine the indirect effect that exists between the components of the model.

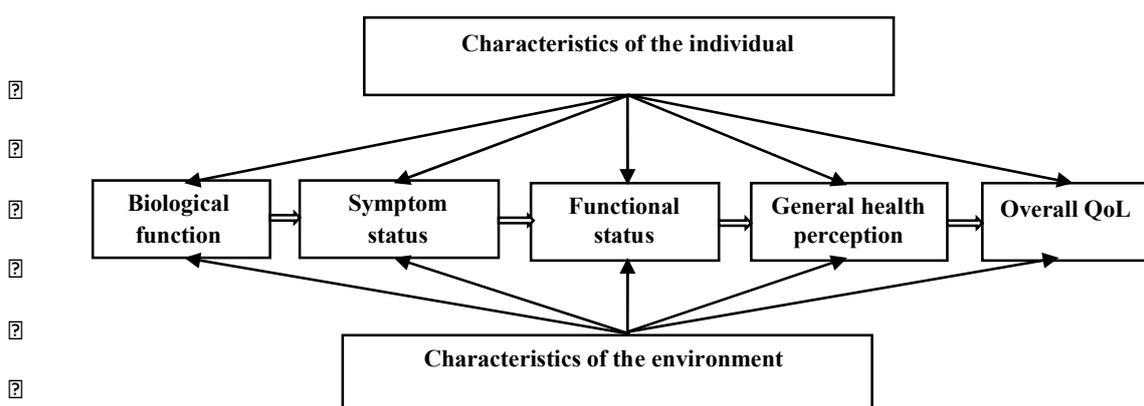


Figure 4.1 Direction of the path analysis as depicted by the revised Wilson and Cleary model

Direct effect of biological function on symptom status

The biological function was measured by three variables: CD4+ count, comorbidity and time since HIV diagnosis. A higher CD4+ count score and no comorbidity denotes a better biological function. A higher score for time since HIV diagnosis denotes a longer period in years since diagnosis. Symptom status was measured by a score for lipodystrophy and

symptoms with a higher score denoting fewer lipodystrophy and symptoms. Functional status was measured by two variables: physical and cognitive functioning and intimate relationship with a higher score signifying better functional status. General health perception was measured by a score for general health and health concern/worries with a higher score denoting better general health perception. For example, higher health concern/worries score signifies fewer or lower health concern/worries. Overall QoL was measured by satisfaction with the healthcare services and global PROQOL-HIV score and a higher score signifying better overall QoL.

Considering the five endogenous components, Figure 4.2 shows that the biological function has a direct effect on symptom status and the biological function has an indirect effect on functional status, general health perception and overall QoL. Therefore, one-way path analysis was used to examine the direct effect of the measures of biological function on the measures of the symptom status. Furthermore, the path analysis was used to examine the indirect effects of the measures of the biological function on the measures of functional status, general health perception and overall QoL as depicted by the revised Wilson and Cleary model.

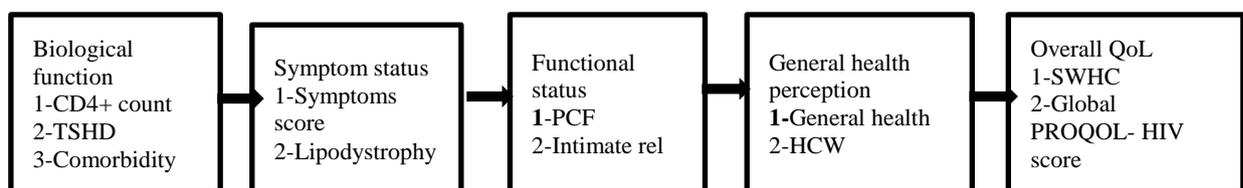


Figure 4.2: Direct effect of biological function on symptom status and the indirect effect of biological function and functional status, general health perception and overall QoL

The results that show the direct effect of biological function on symptom status is presented in Table 4.5. One-way path analysis shows that CD4+ count and comorbidity had a significant direct effect on symptoms score. These results show that the direct effect of comorbidity on symptoms scores is greater than the direct effect of CD4+ count has on the symptoms score. The standardised path coefficient (β) for CD4+ count is 0.103, and this means that after controlling for time since HIV diagnosis and comorbidity, a 1 standard deviation increase in CD4+ count will result in 0.103 standard deviation increase in symptoms score. Also, the standardised path coefficient (β) for comorbidity is -0.131 this means that after controlling for CD4+ count and time since HIV diagnosis, having comorbidity will result in 0.131 standard deviation decrease in symptoms score.

Indirect effect of biological function on functional status, general health perception and overall QoL

Table 4.5 shows the indirect effect of biological function on functional status, general health perception and overall QoL. The indirect effect of the measures of biological function on the measures of the functional status is mediated through the measures of symptom status. Also, the indirect effect of the measures of biological function on the measures of the general health perception is mediated through the measures of symptom status and functional status. Likewise, the indirect effect of the measures of biological function on the measures of the overall QoL is mediated through the measures of symptom status and functional status and general health perception (see Figure 4.2).

The results show that the measures of biological function had no significant indirect effect on functional status, general health perception and overall QoL. Furthermore, the results show that the indirect effect of the measures of the biological function decrease when the relationships go from left to right (that is, from functional status- to- general health perception- to overall QoL).

Direct effect of symptom status on functional status

Symptom status was measured by a score for lipodystrophy and symptoms with a higher score denote fewer lipodystrophy and symptoms. Functional status was measured in by two variables: physical and cognitive functioning and intimate relationship and a higher score signifying better functioning status. Considering 4 of the five endogenous components, Figure 4.3 shows that the symptom status has a direct effect on functional status and the symptom status has an indirect effect on general health perception and overall QoL. Therefore, one-way path analysis was used to examine the direct effect of the measures of symptoms status on the measures of the functional status. Furthermore, the path analysis was used to examine the indirect effects of the measures of the symptom status on the measures of general health perception and overall QoL.

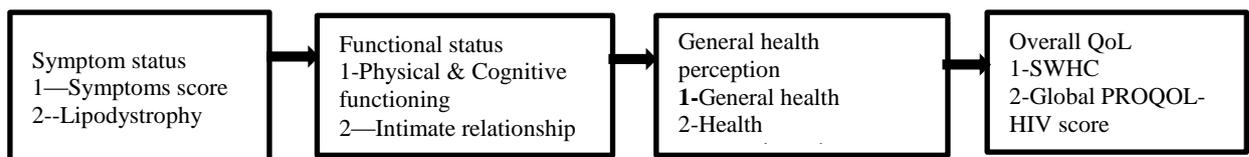


Figure 4.3: Direct effect of symptom status on functional status and the indirect effect of symptom status on general health perception and overall QoL

The results show that symptoms score and lipodystrophy as a measure of symptom status had a direct effect on physical and cognitive functioning. These results also show that the direct effect of symptoms score on physical and cognitive functioning is greater than the direct effect of lipodystrophy's after controlling for measures of the characteristics of the individual and environment. Furthermore, the results show that symptoms score and lipodystrophy as measures of symptom status had a direct effect on intimate relationships as a measure of functional status. These results also show that the direct effect of symptoms score on intimate relationships is greater than the direct effect of lipodystrophy's after controlling for measures of the characteristics of the individual and environment.

Indirect effect of symptom status on general health perception and overall QoL

The indirect effect of the measures of symptom status on the measures of the general health perception is mediated through the measures of functional status. Similarly, the indirect effect of the measures of symptom status on the measures of the overall QoL is mediated through the measures of functional status and general health perception (see Figure 4.3). The results show that symptoms score and lipodystrophy as measures of symptom status had a significant indirect effect on general health as measures of general health perception. The indirect effect of symptoms score on general health is greater than the effect lipodystrophy has. Furthermore, the results show that symptoms score had a significant indirect effect on health concern/worries as a measure of general health perception. However, lipodystrophy as a measure of symptom status had a no significant indirect effect on health worries/concern as measures of general health perception.

The results show that both measures of symptom status (symptoms score and lipodystrophy) had no significant direct effect on satisfaction with the healthcare services as a measure of overall QoL. However, the results show that symptoms score and lipodystrophy had a significant indirect effect on the global PROQOL-HIV score. After controlling for lipodystrophy, measures of the characteristics of the individual and the environment, the results also show that the indirect effect of symptom status decreases when the hypothesised relationships go from left to right (that is, from general health perception to overall QoL).

Direct effect of functional status on general health perception

Functional status was measured by a score for physical and cognitive functioning and intimate relationship (love life and sexual desire). General health perception was measured by a score for general health and health concern/worries and a higher score denoting better general health perception. For example, higher health concern/worries score signifies fewer or lower health concern/worries. Considering three of the five endogenous components,

Figure 4.4 shows that the functional status has a direct effect on general health perception and the functional status has an indirect effect on overall QoL. Therefore, one-way path analysis was used to examine the direct effect of the measures of functional status on the measures of the general health perception. Furthermore, the path analysis was used to examine the indirect effects of the measures of the functional status on the measures of overall QoL as depicted by the revised Wilson and Cleary model.

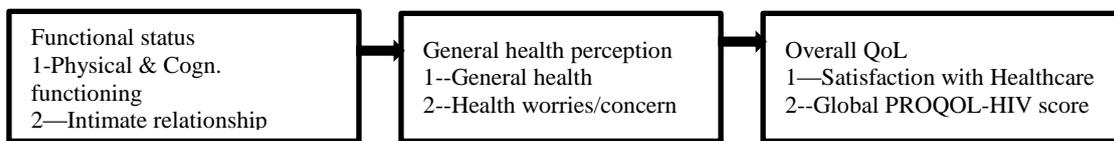


Figure 4.4 Direct effect of functional status on general health perception and the indirect effect of functional status on overall QoL

The results show that physical and cognitive functioning and intimate relationships had a significant direct effect on general health. The direct effect of physical and cognitive functioning on general health is greater than the direct effect of intimate relationship has. Furthermore, the results show that physical and cognitive functioning had a significant direct effect on health concern/worries after controlling for intimate relationships, measures of the characteristics of the individual and environment. However, intimate relationships had no significant direct effect on health concern/worries.

Indirect effect of functional status on overall QoL

The indirect effect of the measures of functional status on the measures of the overall QoL is mediated through the measures of general health perception (see Figure 4.4). The results show that physical and cognitive functioning and intimate relationships as measures of

functional status had no significant indirect effect on satisfaction with the healthcare services as a measure of overall QoL.

However, the results show that physical and cognitive functioning and intimate relationships as measures of functional status had a significant indirect effect on the global PROQOL-HIV score as a measure of overall QoL. The indirect effect of intimate relationship on global PROQOL-HIV score is greater than the effect physical and cognitive functioning has. The standardised path coefficient (β) for physical and cognitive functioning and intimate relationship is 0.137 and 0.155, this means that after controlling for measures of characteristics of the individual and environment, a 1 standard deviation increase in physical and cognitive functioning and having a high intimate relationship will result in 0.137 and 0.155 standard deviation increase in global PROQOL-HIV score respectively.

Direct effect of general health perception on overall QoL

General health perception was measured by a score for health concern/worries score and general health score. The overall QoL was measured by satisfaction with the healthcare services and global PROQOL-HIV score, and a higher score signifies better overall QoL. Considering two of the five endogenous components, Figure 4.4 shows that the general health perception has a direct effect on overall QoL. Therefore, one-way path analysis was used to examine the direct effect of the measures of general health perception on the measures of the overall QoL.

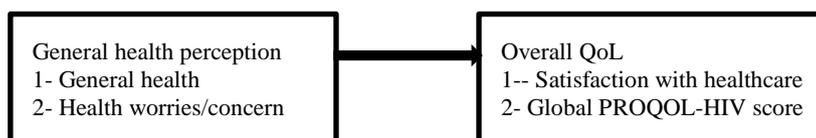


Figure 4.5 Direct effect of general health perception on overall QoL

The results show that general health and health concern/worries had no significant direct effect on satisfaction with the healthcare services. However, the results show that general health and health concern/worries had a significant direct effect on the global PROQOL-HIV score. The direct effect of general health on the global PROQOL-HIV score is greater than the effect health concern/worries score has after controlling for measures of the characteristics of the individual and environment.

Table 4.5: One-way path analysis of the direct effect and indirect effect between the five endogenous components of the revised Wilson and Cleary model (N = 443)

Dependent variable Independent variables ↓	Model 1 —Symptom status		Model 2 —Functional status		Model 3 General health perception		Model 4 Overall QoL	
	Symp S	Lipodys	PCF	IR	GH	HCW	SWHC	GPS
Biological function								
CD4+ count	0.103*	0.145**	0.024	-0.006	0.065	-0.034	-0.018	-0.003
TSHD	-0.057	-0.109*	-0.019	-0.013	-0.019	0.040	0.014	-0.004
CoM	-0.131**	-0.038	-0.040	-0.044	0.013	-0.070	-0.009	0.000
Symptom status								
Symptoms score			0.535**	0.189**	0.397**	0.127**	-0.022	0.131**
Lipodystrophy			0.125**	0.187**	0.284**	0.001	0.116	0.153**
Functional status								
PCF					0.387**	0.152**	0.074	0.137**
Intimate relationships					0.154**	0.061	-0.086	0.155**
General health perception								
General health							-0.088	0.350**
HCW							-0.043	0.185**

Notes: TSHD = time since HIV diagnosis; CoM = Comorbidity; Symp S = Symptoms score; Lipodys = Lipodystrophy; PCF = Physical and cognitive functioning; IR = Intimate relationship; GH = General health; HCW = Health concern/worries; SWHC = Satisfaction with the healthcare; GPS = Global PROQOL-HIV score; ** $p < 0.01$; * $p < 0.05$ Bold = direct effect; non-bold = indirect effect

Direct effect of characteristics of the individual on biological function, symptom status, functional status, general health perception and overall QoL

The characteristics of the individual were measured by eleven variables: age, gender, marital status, educational level, tobacco smoking behaviour, alcohol use, and illicit drug use shown in Table 4.1. Furthermore, other characteristics of the individual were presented in Table 4.2, and these include emotional distress, future, stigmatisation and treatment impact. Characteristics of the environment were measured by five variables, namely social relationship, social support, spirituality and financial difficulties (see Table 4.3).

Figure 4.6 shows the direction of the path analysis to examine the direct effect of the measures of the characteristics of the individual and the environment on the measures of biological function, symptom status, functional status, general health perceptions and overall QoL.

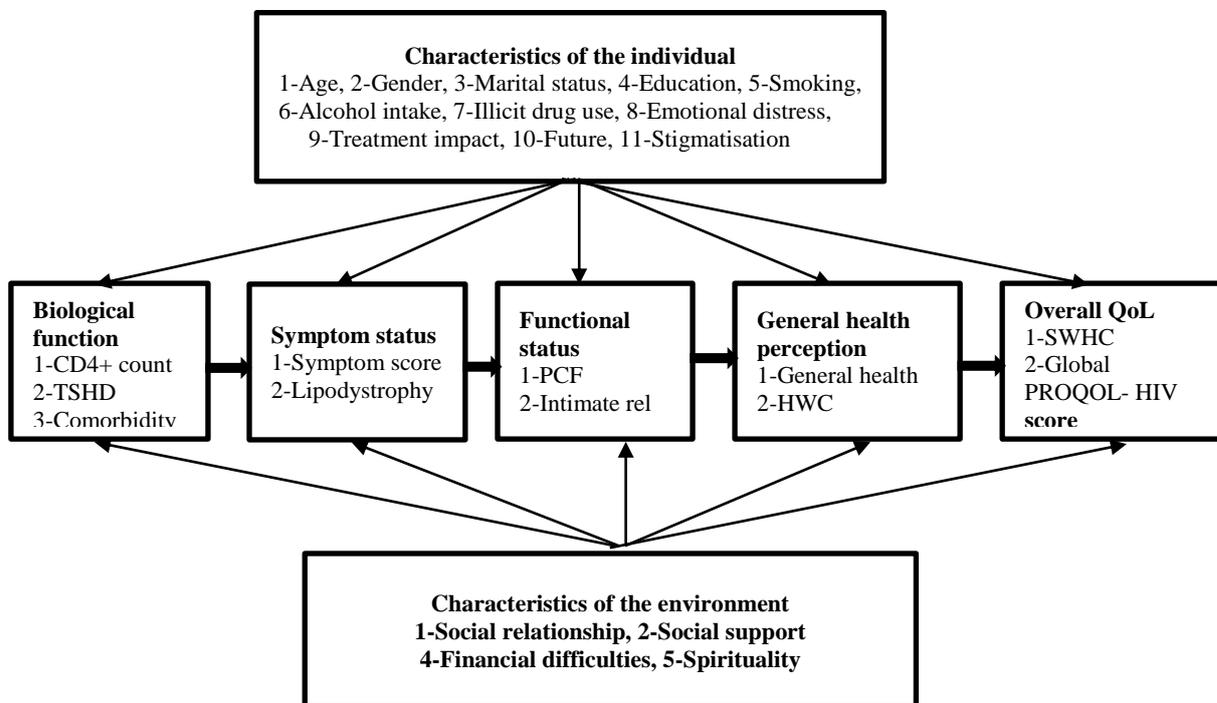


Figure 4.6 Direct effect of the characteristics of the individual and the environment on biological function, symptom status, functional status, general health perception and overall QoL

Direct effect of characteristics of the individual on biological function

Table 4.6 shows the results of the one-way path analysis of the direct effect of the measures of the characteristics of the individual on biological function, symptom status, functional status, general health perceptions and overall QoL. The results in model 1 show that sex and treatment impact (these include: better adherence to ART, feeling less stigmatised taking ART, and having fewer ART side effects) had significant direct effects on CD4+ count. The direct effect of the treatment impact on CD4+ count is greater than the effect sex has. After controlling for all the remaining measure of the characteristics of the individual and the measures of the characteristics of the environment, female participants had 0.190 standard deviation higher CD4+ count than male participants. Similarly, the standardised path coefficient (β) for treatment impact is 0.193, this means that after controlling for all the remaining measure of the characteristics of the individual and all the measures of the characteristics of the environment, a one standard deviation increase in treatment impact will result in 0.193 standard deviation increase in CD4+ count.

However, age, marital status, level of education, tobacco smoking, alcohol use, illicit drug use, emotional distress, future and stigmatisation had no significant direct effects on CD4+ count. Also these results show that 11.9% of the variance in CD4+ count is accounted for by the variance in all the measures of the characteristics of the individual and characteristics of the environment.

The results show that age and gender and educational level had a significant direct effect on time since HIV diagnosis. The direct effect of age on time since HIV diagnosis is greater than the effect gender and educational level have (in this particular order: age > gender > educational level) after controlling for all the remaining measure of the characteristics of the individual and all the measures of the characteristics of the environment. However, all the remaining measures of the characteristics of the individual used in the analysis did not have

a significant direct effect on the time since HIV diagnosis. Also these results show that 12.2% of the variance in time since HIV diagnosis is accounted for by the variance in all the measures of the characteristics of the individual (age, gender, marital status, level of education, tobacco smoking behaviour, alcohol use, illicit drug use, emotional distress, future, treatment impact and stigmatisation) and the measures of characteristics of the environment (social relationship, social support, financial difficulties and spirituality).

The results show that age, marital status, tobacco smoking and alcohol intake had a significant direct effect on comorbidity. The direct effect of age on comorbidity is greater than the effect of alcohol intake, tobacco smoking behaviour and marital status. In this particular order, age > alcohol intake > tobacco smoking behaviour > marital status after controlling for all the remaining measure of the characteristics of the individual and all the measures of the characteristics of the environment. However, there is no significant direct effect of sex, educational level, illicit drug use, emotional distress, future, treatment impact and stigmatisation on comorbidity as a measure of biological function.

The results also show that 16% of the variance in comorbidity is accounted for by the variance in all the measures of the characteristics of the individual and the measures of the characteristics of the environment. The results show that the measures of the characteristics of the individual and the measures of the characteristics of the environment explained greater variance in comorbidity than the variance they explained for time since HIV diagnosis and CD4+ count. Whilst the measures of the characteristics of the individual and the measures of the characteristics of the environment explained greater variance in time since HIV diagnosis than the variance in CD4+ count.

Direct effect of characteristics of the individual on symptom status

The results show that educational level and emotional distress had a significant direct effect on symptoms score. The direct effect of emotional distress on symptoms score is greater than the effect of educational level. Also, the results show that having a college/university education is associated with in 0.15 standard deviation increase in symptoms score. In addition, 40% of the variability in symptoms score is explained by the variance in the measures of the biological function and the measures of both characteristics of the individual and environment. However, the results show that there is no significant direct effect of age, sex, tobacco smoking behaviour, alcohol intake, illicit drug use future, stigmatisation and treatment impact on symptoms score.

The results show that age, educational level and emotional distress impact had a significant direct effect on lipodystrophy score. The direct effect of emotional distress on lipodystrophy is greater than the effect of age and educational after controlling for all the remaining measures of the characteristics of the individual and all the measures of the characteristics of the environment. However, the results show that sex, marital status, smoking behaviour, alcohol intake, illicit drug use, future, treatment impact and stigmatisation had no significant direct effect on lipodystrophy.

Furthermore, 42.6% of the variance in lipodystrophy is accounted for by the variance in the measures of the biological function, measures of the characteristics of the individual and the measures of the characteristics of the environment. The results show that the measures of biological function, the measures of the characteristics of the individual and measures of the characteristics of the environment explained greater variance in lipodystrophy score than the variance they explained symptoms score.

Direct effect of characteristics of the individual on functional status

The results show that age, marital status emotional distress and treatment impact had a significant direct effect on physical and cognitive functioning. The direct effect of age on physical and cognitive functioning is greater than the effect of emotional distress, treatment impact and marital status (age > emotional distress > treatment impact > marital status) after controlling for all the remaining measure of the characteristics of the individual and the measures of the characteristics of the environment. Additionally, 61.7% of the variability in physical and cognitive functioning is explained by the variance in the measures of the symptom status, the measures of the characteristics of the individual and the characteristics of the environment. However, the results show that the gender, educational level, smoking behaviour, alcohol intake, illicit drug use, future and stigmatisation had no significant direct effect on physical and cognitive functioning.

The results show that age, marital status and stigmatisation had a significant direct effect on intimate relationships. The direct effect of stigmatisation on intimate relationships is greater than the effect of marital status and age (stigmatisation > marital status > age) after controlling for the remaining measures of the characteristics of the individual and all the measures of the environment. Also, the results show that being not married is associated with lower intimate relationships score after controlling for the remaining measures of the characteristics of the individual and all the measures of the environment. Furthermore, having a high stigmatisation score is associated with high in intimate relationships after controlling for the remaining measures of the characteristics of the individual and all the measures of the environment. However, gender, educational level, smoking behaviour, alcohol use, illicit drug use, emotional distress, future and treatment impact had no significant direct effect on intimate relationships. Furthermore, 29.3% of the variability in intimate relationships is explained by the variance in the measures of the symptom status,

the measures of both the characteristics of the individual and the characteristics of the environment. The results show that the measures of symptom status, the measures of the characteristics of the individual and the characteristics of the environment explained greater variance in physical and cognitive functioning than the variance they explained intimate relationships.

Direct effect of characteristics of the individual on general health perception

The results show that educational level, emotional distress and treatment impact had a significant direct effect on general health as a measure of general health perception. The direct effect of emotional distress is greater than that of level of education, treatment impact, age, alcohol intake and marital status. In other words, in this particular order emotion distress > level of education > treatment impact after controlling for the remaining measures of the characteristics of the individual and the measures of the characteristics of the environment. However, the results show that age, gender, marital status, smoking behaviour, alcohol intake, illicit drug use, future and stigmatisation had no significant direct effect on general health.

Furthermore, 51.1% of variance in general health is explained by the variance in the measures of functional status, all the eleven measures of the characteristics of the individual in the model (age, gender, marital status, level of education, tobacco smoking, alcohol intake, illicit drug use, emotional distress, treatment impact, future, and stigmatisation) and the four measures of the characteristics of the environment (social relationship, social support, financial difficulties and spirituality).

The results show that emotional distress and treatment impact had a significant direct effect on health concern/worries as a measure of general health perception. The direct effect of emotional distress on health concern/worries is greater than the effect of treatment impact

after controlling for the remaining measures of the characteristics of the individual and the measures of the characteristics of the environment. However, the results show that age, gender, education level, smoking behaviour, alcohol intake, illicit drug use, future and stigmatisation had no significant direct effect on health concern/worries. In addition, 36.9% of the variability in health concern/worries is accounted for by the variance in the measures of functional status, the measures of the characteristics of the individual and the measures of the characteristics of the environment in the model. The results show that the measures functional status, measures of the characteristics of the individual and the characteristics of the environment explained greater variance in general health than the variance they explained health concern/worries.

Direct effect of characteristics of the individual on overall QoL

The results show that age, treatment impact and future had a significant direct effect on satisfaction with the healthcare services (see Table 4.5). The direct effect of treatment impact on satisfaction with the healthcare services is greater than the effect future subscale and age have. In this particular order, the effect of treatment impact > future > age. Also the results show that the standardised path coefficient of future and treatment impact is 0.157 and 0.169 respectively. This denotes that, a 1 standard deviation increase in future and treatment impact will result in 0.157 and 0.169 standard deviation increase in satisfaction with the healthcare services after controlling for the remaining measures of the characteristics of the individual and all the measures of the characteristics of the environment (social relationship, social support, financial difficulties and spirituality). Similarly, the standardised path coefficient of age is -0.092, this means that a 1 standard deviation increase in age is associated with low satisfaction with the healthcare services after controlling for the remaining measures of the characteristics of the individual and all the measures of the characteristics of the environment.

However, gender, marital status, educational level, smoking behaviour, alcohol intake, illicit drug use, emotional distress and stigmatisation had no significant direct effect on satisfaction with the healthcare services. Furthermore, 26.2% of variability in satisfaction with the healthcare services is accounted for by the variance in the measures of general health perception, the measures of the characteristics of the individual and the measures of the characteristics of the environment.

The results show that age, marital status emotional distress, treatment impact, future and stigmatisation had a significant direct effect on global PROQOL-HIV score as measure of overall QoL. In this order, the direct effect of emotional distress is > future > treatment impact > stigmatisation > age > marital status after controlling for the remaining measures of the characteristics of the individual and all the measures of the characteristics of the environment.

However, gender, educational level, smoking behaviour, alcohol intake, and illicit drug use had no significant direct effect on global PROQOL-HIV score. Furthermore, 87.1% of the variance in global PROQOL-HIV score is accounted for by the variance in all the measures of general health perception (including the all the variances of the measures of biological function, symptoms status and functional status through general health perception), the characteristics of the individual and that of characteristics of the environment. The results show that the measure of general health perception, the measures of the characteristics of the individual and the measures of the characteristics of the environment explained greater variance in global PROQOL-HIV score than the variance they explained satisfaction with the healthcare services.

Direct effect of characteristics of the environment on biological function

Table 4.5 shows the results of the one-way path analysis of the direct effect of the measures of the characteristics of the environment on biological function, symptom status, functional status, general health perceptions and overall QoL. The results show that social relationship, social support, financial difficulties and spirituality had no significant direct effect on CD4+ count, time since HIV diagnosis and comorbidity as measures of biological function.

Direct effect of characteristics of the environment on symptom status

The results show that social relationship had a significant direct effect on symptoms score. The standardise path coefficient for social relationship is 0.157 and this means that, having a high social relationship is associated with 0.157 standard deviation increase in symptoms score after controlling for all the measures of the characteristics of the individual and the remaining measures of the characteristics of the environment (social support, financial difficulties and spirituality). However, social support, financial difficulties and spirituality had no significant direct effect on symptom score.

Furthermore, the results show that social relationship and financial difficulties had a direct effect on lipodystrophy. The effect of social relationship on lipodystrophy is greater than the effect financial difficulties score has. However, social support and spirituality had no significant direct effect on lipodystrophy.

Direct effect of characteristics of the environment on functional status

The results show that social relationship, social relationship, financial difficulties and spirituality had no significant direct effect on physical and cognitive functioning as a measure of functional status. Furthermore, financial difficulties and spirituality had no significant direct effect on intimate relationship as a measure of functional status. However, social relationship and social support had a significant direct effect on intimate relationship. The effect of social support on intimate relationship is greater than the effect that social

relationship. The results also show that having high social relationship is associated with having high intimate relationship and 0.101 standard deviation decrease in social support is associated with high intimate relationship.

Direct effect of characteristics of the environment on general health perception

The results show that social support and financial difficulties had a significant direct effect on general health as a measure of general health perception. The direct effect of financial difficulties on general health is greater than the effect social support has. The results show that a 1 standard deviation increase social support will result in 0.115 standard deviation increase in general health after controlling for all the measures of the characteristics of the individual and the remaining measures of the characteristics of the environment (social relationship, financial difficulties and spirituality). Also, having high financial difficulties is associated with 0.119 standard deviation increase general health after controlling for all the measures of the characteristics of the individual and the remaining measures of the characteristics of the environment (social support, social relationship and spirituality). However, social relationship and spirituality had no significant direct effect on general health. Furthermore, social relationship, social support, financial difficulties and spirituality had no significant direct effect on health concern/worries as a measure of general health perception.

Direct effect of characteristics of the environment on overall QoL

The results show that the social relationship had a significant direct effect on satisfaction with the healthcare services. The path coefficient of social relationship is 0.194, this means that having a high social relationship score is associated with an increase in satisfaction with the healthcare services after controlling for all the measures of the characteristics of the individual and the remaining measures of the characteristics of the environment (social

support, financial difficulties and spirituality). However, social support, financial difficulties and spirituality had no significant direct effect on satisfaction with the healthcare services.

The results show that the social relationship, social support, financial difficulties and spirituality had a significant direct effect on global PROQOL-HIV score. The direct effect of social relationship on global PROQOL-HIV score is greater than the effect spirituality, financial difficulties and social support (that is, social relationship > spirituality > financial difficulties > social support) after controlling for all the measures of the characteristics of the individual.

Table 4.6: One-way path analysis of the direct effect of characteristics of the individual and the environment on biological function, symptom status, functional status, general health perception and overall QoL (N = 443)

DV →	Model 1			Model 2		Model 3		Model 4		Model 5	
	Biological function			Symptom status		Functional status		General health perception		Overall QoL	
	CD4	TSHD	CoM	Symp S	Lipodys	PCF	IR	GH	HCW	SWHC	GPS
IV ↓	β	β	β	β	β	β	β	β	β	β	β
C o Individual											
Age	-0.033	0.293**	0.222**	-0.067	-0.108**	-0.126**	-0.083*	-0.054	-0.071	-0.092*	-0.044*
Sex	0.190**	0.136*	-0.056	0.011	0.068	-0.022	-0.065	0.062	-0.028	0.092	0.015
Marital status	-0.034	-0.010	0.098*	-0.046	-0.066	-0.071*	-0.121**	-0.010	-0.044	-0.066	-0.038*
Educ level	0.038	0.104*	0.027	0.150**	0.108**	0.034	0.044	0.147**	0.058	0.045	0.0001
Smoking beh	-0.033	-0.082	0.111*	0.002	0.021	-0.041	-0.069	0.041	-0.020	-0.052	-0.023
Alcohol intake	-0.022	0.091	0.179**	-0.022	-0.024	-0.033	-0.034	-0.063	-0.034	0.018	-0.012
Illicit drug use	-0.008	0.001	0.005	-0.026	0	-0.019	0.008	0.047	0.046	-0.049	-0.011
Emotional d	-0.012	0.047	-0.022	0.405**	0.321**	0.081*	0.085	0.149**	0.283**	0.08	0.214**
Future	0.033	-0.034	0.032	0.014	-0.003	0.054	0.009	-0.01	0.040	0.157**	0.157**
Treat impact	0.193**	0.063	-0.034	0.067	0.049	0.076*	0.037	0.085*	0.193**	0.169**	0.102*
Stigmatisation	0.026	-0.037	-0.026	0.047	0.029	0.06	0.139**	0.015	0.016	-0.063	0.093*
C o Environment											
Social rel	0.033	-0.023	-0.044	0.157**	0.266**	0.04	0.09*	0.01	0.049	0.194**	0.179**
Social support	0.022	-0.021	0.018	0.044	0.026	-0.039	-0.101**	0.115**	-0.022	-0.013	-0.038*
Fin difficulties	0.035	-0.015	-0.004	-0.037	0.130**	-0.001	0.047	0.119**	0.032	0.161	0.106**
Spirituality	0.017	-0.017	-0.067	0.049	-0.045	0.048	0.014	-0.045	0.039	0.073	0.119**
R ²	0.119	0.122	0.160	0.400	0.426	0.617	0.452	0.511	0.369	0.262	0.871

Note, CD4 = CD4+ count; TSHD = time since HIV diagnosis; CoM = Comorbidity; Symp S = Symptoms score; Lipodys = Lipodystrophy; PCF = Physical and cognitive functioning; IR = Intimate relationship; GH = General health; HCW = Health concern/worries; SWHC = Satisfaction with the healthcare; GPS = Global PROQOL-HIV score; C o Individual = Characteristics of the individual; C o Environment = Characteristics of the environment; Educ level = Educational level; Smoking beh = Smoking behaviour; Emotional d = Emotional distress; Treat impact = Treatment impact; Social rel = Social relationship; Fin difficulties = Financial difficulties; ** $p < 0.01$; * $p < 0.05$

Structural equation modelling (SEM)

This section describes the SEM used to assess the model fit of the revised Wilson and Cleary model. SEM is a multivariate statistical analysis and was used to analyse the structural relationships between the measured variables and the latent constructs described in the model. This analysis was conducted to assess research objective three. Two-step SEM (specifically CFA) was conducted because the revised Wilson and Cleary already has a proposed direction of causal relationship to be tested (Blunch 2013). In this SEM, the term ‘indicator’ was used to describe all parcelled items (Bandalos 2008, Little et al 2002) discussed in Chapter 3 and detailed in Appendix X (i.e., emotional distress, symptoms score, physical and cognitive functioning, health concern, lipodystrophy, treatment impact, and intimate relationship). In contrast, ‘observed variables’ was used to describe items not parcelled (for instance, sociodemographic variables, CD4+ count, time since HIV diagnosis, comorbidity, spirituality, general health, financial difficulties, etc.). Indicators were parcelled as the average of multiple items of a subscale (Little et al 2002) while observed variables single items that were directly measured (Bandalos 2008). Both indicators and observed variables were used to measure latent (unobserved) variables in this SEM (Bandalos 2008, Little et al 2002).

In SEM, when parcelled items are used then the parcelled aggregate measure is equal to the ‘latent’ variable and in the case of parcelled data when it is unidimensional the term latent variable still holds (Little et al 2002). Seven latent variables (i.e., biological functioning, symptom status, functional status, general health perception, overall QoL, characteristics of the individual and characteristics of the environment) of the revised Wilson and Cleary model was used in this SEM. For instance, three observed items (CD4+ counts, time since HIV diagnosis and comorbidity) were used to measure biological function. Two items each to measure symptom status, and functional status (latent variables) that are unidimensional

and parcelled. In this case, symptom status with two parcelled (symptoms score and lipodystrophy) thus, symptom status is a latent construct of symptoms score and lipodystrophy (Bandalos 2008, Little et al 2002). Also, in a situation where both observed variable and parcelled item (indicator) were used to measure a latent variable (for example, general health perception and characteristics of the individual), the latent variable remained construct of both the observed variable and parcelled item (Little et al 2002).

Step 1 is the measurement model conducted and serves as a preliminary model fit assessment of the seven latent variables of the revised Wilson and Cleary model. This first step helps to assess the possibility that the data will fit the model. In this step, it was assumed that all the latent variables covary to test goodness-of-fit. If the model fit is assumed in step 1 thus, a final model fit analysis of the model would be assessed in the direction of the causal effect among the seven latent variables hypothesised by revised Wilson and Cleary model.

Step 2 is the final structural model which assesses the good-of-fit of the revised Wilson and Cleary model based on the proposed directions of causal relationships in the model. The revised Wilson and Cleary model has five endogenous latent variables (that is, biological function, symptom status, functional status, general health perception and overall QoL) and two exogenous latent variables (characteristics of the individual and the characteristics of the environment).

Step 1: The measurement model

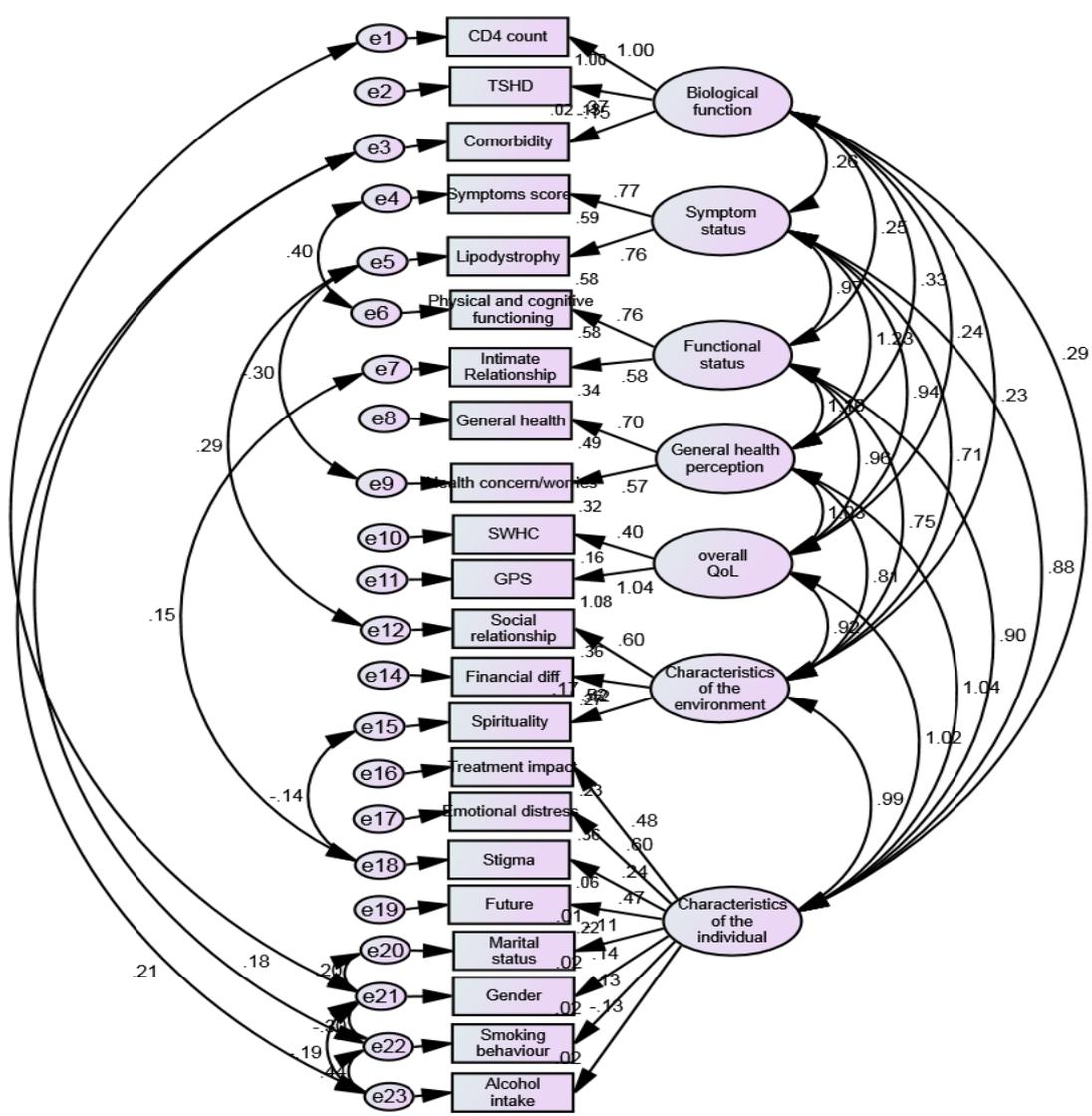
Figure 4.7 shows the measurement model of the tested hypothesised model. In the measurement model there were nineteen observed variables collected from PROQOL-HIV questionnaire, ISEL-SF16 question, sociodemographic form, and selected variables from the participants' medical case notes. These were loaded onto their corresponding seven latent

variables as depicted by the revised Wilson and Cleary model. Also in the measurement model were seven indicators parcelled from a total of thirteen items in the PROQOL-HIV questionnaire which corresponded with the seven latent constructs: emotional distress, symptoms score, physical and cognitive functioning, health concern, lipodystrophy, treatment impact, and intimate relationship.

The analysis modification indices (MI) suggested 18 number of modifications before a reasonable model fit of the revised Wilson and Cleary model was assumed. All the eighteen MI were summarised in Table 4.7. In step 1, when all observed variables and parcelled indicators were inserted into the AMOS software as described by the model, the analysis was run. The output shows that the hypothesised model was over-identified with $df = 278$ however, with an inadmissible solution. The result of the maximum likelihood estimated chi-square is $(\chi_M^2 (278) = 1071.134, p < 0.001)$. However, the critical ratio (CR) of the regression weights of four observed variables that is, social support ($B = -0.049, CR = -1.434, p = 0.152$), age ($B = 0.035, CR = 1.461, p = 0.144$), educational status ($B = 0.002, CR = 0.878, p = 0.380$) and illicit drug use ($B = 0.000, CR = -0.159, p = 0.874$) were statistically non-significant. This indicates that these variables were not needed in the model. The null hypothesis of the estimate was zero and the absolute value of the CR exceeds ± 1.96 (two-tailed). Therefore, there was evidence at the 5% level to accept the null hypothesis and conclude that the estimate of the variables is significantly not different from zero.

Step 2 to step 5, after the systematic removal of social support, age, educational status and illicit drug use from the model, the result of the maximum likelihood estimated chi-square is $(\chi_M^2 (188) = 752.997, p < 0.001)$ (see step 2 to 5 on Table 4.7). After the four observed variables were deleted from the model as recommended by SEM analysis, twenty-two

observed variables were finally used throughout the analysis. The result shows that the data poorly fit model, however, with an admissible solution.



Chi-square = 423.236
 $df = 177, p = <0.001$
 $CMIN/df = 2.391$
 $CFI = 0.935$
 $RMSEA = 0.056$ (90% CI: 0.049 - 0.063, $p = 0.07$)

Figure 4.7: Measurement model of the seven latent variables of the revised Wilson and Cleary model with finally 22 variables (7 indicators and 15 observed) and post-hoc modifications

Table 4.7: Model modification summary of the CFA result of the final 7-factor measurement (N = 443)

Model	Model fit			
	χ^2 (<i>p</i> -value)	χ^2 /df	CFI	RMSEA
1. Seven factor CFA, 26 variables	1071.134 (<0.001)	3.853	0.803	0.080
2. Deleted illicit drug use	1047.611 (<0.001)	4.124	0.803	0.084
3. Deleted educational level	941.490 (<0.001)	4.074	0.820	0.083
4. Deleted social support	906.06 (<0.001)	4.335	0.823	0.087
5. Deleted age	752.997 (<0.001)	4.005	0.851	0.082
6. Constraining e1 = 0	753.508 (<0.001)	3.987	0.851	0.082
7. Added path e22 (smoking behaviour) to e23 (alcohol intake)	652.358 (<0.001)	3.470	0.878	0.075
8. Added path e21 (gender) to e22 (smoking behaviour)	620.832 (<0.001)	3.320	0.886	0.072
9. Added path e20 (marital status) to e21 (gender)	559.334 (<0.001)	3.222	0.891	0.071
10. Added path e4 (symptoms score) to e6 (physical /cog functioning)	559.690 (<0.001)	3.025	0.901	0.068
11. Added path e5 (lipodystrophy) to e9 (health concern/worries)	532.532 (<0.001)	2.894	0.908	0.065
12. Added path e21 (gender) to e23 (alcohol intake)	506.931 (<0.001)	2.770	0.915	0.063
13. Added path e5 (lipodystrophy) to e12 (social relationship)	479.404 (<0.001)	2.634	0.922	0.061
14. Added path e1 (CD4+ count) to e21 (gender)	467.972 (<0.001)	2.585	0.924	0.060
15. Added path e3 (comorbidity) to e23 (alcohol intake)	457.960 (<0.001)	2.544	0.927	0.059
16. Added path e3 (comorbidity) to e22 (smoking behaviour)	443.120 (<0.001)	2.476	0.931	0.059
17. Added path e7 (intimate relationship) to e18 (stigmatisation)	432.253 (<0.001)	2.428	0.933	0.057
18. Added path e15 (spirituality) to e13 (stigmatisation)	423.236 (<0.001)	2.391	0.935	0.056

Note: Physical /cog functioning = Physical and cognitive functioning

In step 6, the estimates output shows that the CR of the variance of error term e1 (CR = -19332.245, $p = 0.571$) is statistically not significant. The null hypothesis is that the estimate is zero. The absolute value of the CR is below 1.96 (two-tailed). Thus, it is evident that at the 5% level to accept the null hypothesis and it is concluded that the estimate of the parameter is not significantly different from zero. For the remaining estimated parameters in the model, the CR indicates that the estimates are statistically and significantly differ from zero. This implies that e1 is probably not needed in the model. Because this test is asymptotically correct, a chi-squared comparison test was conducted to test the hypothesis that $\text{var}_1(e1) = 0$. A critical value of 3.84 was used for comparison of a change in a degree of freedom by removing a parameter. After constraining $\text{var}_1(e1) = 0$, the change in chi-square is 0.510, $p = 0.475$ as result of increase of the degree of freedom by 1. This implies that the rise in chi-square is less than the critical value of 3.84. The null hypothesis is accepted, and therefore, e1 is not significant in the model.

The chi-square statistic of the new 22-item measurement model is ($\chi^2_M(189) = 753.508$, $p < 0.001$) and still the model fit is poor. Post-hoc model modification was explored to improve the fit of the 7-latent variables measurement model. MI result recommended that adding a path between the residual covariance of smoking behaviour (e22) and alcohol intake (e21) would significantly improve the model by reducing the chi-square by nearly 83.564. This was a meaningful parameter to add since both of the items are measures of characteristics of the individual. Therefore, one would expect them to be correlated. The model was tested again with this additional path. The result showed that the overall fit of the model was improved, but the data were still a poor fit to the model. The result of the chi-square difference test shows that the fit of the modified model was significantly improved from the original unconstrained 7-factor CFA model ($\chi^2_D(1) = 753.508 - 652.358 = 101.15$, $p < 0.001$). See step 7 of Table 4.7. The MI in step 8 of the model specified that the

error terms of sex (e21) and smoking behaviour (e22) are correlated. The MI output shows that adding a path between the residual covariance of the error term of sex (e21) and smoking behaviour (e22) would improve the model by reducing the chi-square statistics by nearly 29.851. This was a reasonable parameter to add because studies have shown that there are sex differences in smoking behaviour (mostly that males tend to smoke more than females) and both measured variables are components of the same latent variable 'characteristics of the individual'. Step 8 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 652.358 - 620.832 = 31.526, p < 0.001$).

As recommended by the MI, the model was specified again so that the error terms of marital status (e20) and sex (e21) are correlated. The MI shows that the model would improve the model by reducing the chi-square statistics by nearly 48.818. Step 9 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 620.832 - 559.334 = 61.498, p < 0.001$).

Step 10, the model was specified again so that the error terms of symptom score (e4) and physical and cognitive functioning (e6) are correlated. The MI shows that the model would improve the model by reducing the chi-square statistics by nearly 16.375. This was a reasonable parameter to add because studies have shown that people with lower symptoms have better functioning. Step 10 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 559.690 - 559.334 = 0.356, p < 0.001$).

Step 11, the model was specified again so that the error terms of lipodystrophy (e5) and health concern/worries (e9) are correlated. The MI shows that by adding a path between the residual covariance of the error term of lipodystrophy (e5) and health concern/worries (e9)

would improve the model by reducing the chi-square statistics by nearly 16.872. This was a reasonable parameter to add because people with worse lipodystrophy score tend to have high health worries/concern. Step 11 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 559.69 - 532.532 = 27.158, p = < 0.001$).

The MI in step 12 recommended that the error terms of gender (e21) and alcohol intake (e23) are correlated. The MI shows that by adding a path between the residual covariance of the error term of gender (e21) and alcohol intake (e23) would improve the model by reducing the chi-square statistics by nearly 18.345. This was a reasonable parameter to add as it is well known gender has an influence on alcohol use (males tend to use alcohol more than females). Step 12 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 532.532 - 506.931 = 25.601, p = < 0.001$).

As recommended by the MI, the model was specified again so that the error terms of lipodystrophy (e5) and social relationship (e12) are correlated. The MI shows that by adding a path between the residual covariance of the error term of lipodystrophy (e5) and social relationship (e23) would improve the model by reducing the chi-square statistics by nearly 18.140. Step 13 of Table 4.7 show that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 506.931 - 479.404 = 27.527, p = < 0.001$).

Step 14, the model was specified again so that the error terms of CD4+ count (e1) and gender (e21) are correlated. The MI shows that by adding a path between the residual covariance of the error term of CD4+ count (e1) and gender (e23) would improve the model by reducing the chi-square statistics by nearly 9.571. This was a reasonable parameter to add because gender influences CD4+ count, as males tend to have higher CD4+ count than

females. Step 14 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 479.404 - 467.972 = 11.432, p = < 0.001$).

As recommended by the MI, the model was specified again so that the error terms of comorbidity (e3) and alcohol intake (e23) are correlated. The MI shows that by adding a path between the residual covariance of the error term of comorbidity (e3) and alcohol intake (e23) would improve the model by reducing the chi-square statistics by nearly 8.768. This was a reasonable parameter to add because alcohol use increases the risk of comorbidity in patients living with chronic diseases. Step 15 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 467.972 - 457.96 = 10.012, p = < 0.001$).

As recommended by the MI, the model was specified again so that the error terms of comorbidity (e3) and smoking behaviour (e22) are correlated. The MI shows that by adding a path between the residual covariance of the error term of comorbidity (e3) and smoking behaviour (e22) would improve the model by reducing the chi-square statistics by nearly 8.371. This was a reasonable parameter to add because tobacco smoking increases the risk of comorbidity in patients living with chronic diseases. Step 16 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 457.96 - 443.12 = 14.84, p = < 0.001$).

Step 17, the model was specified again so that the error terms of intimate relationship (e7) and stigmatisation (e18) are correlated. The MI shows that by adding a path between the residual covariance of the error term of intimate relationship (e7) and stigmatisation (e18) would improve the model by reducing the chi-square statistics by nearly 8.682. This was a reasonable parameter to add because stigmatisation has negative influence on intimate

relationship. Step 17 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 443.12 - 432.253 = 10.867, p = < 0.001$).

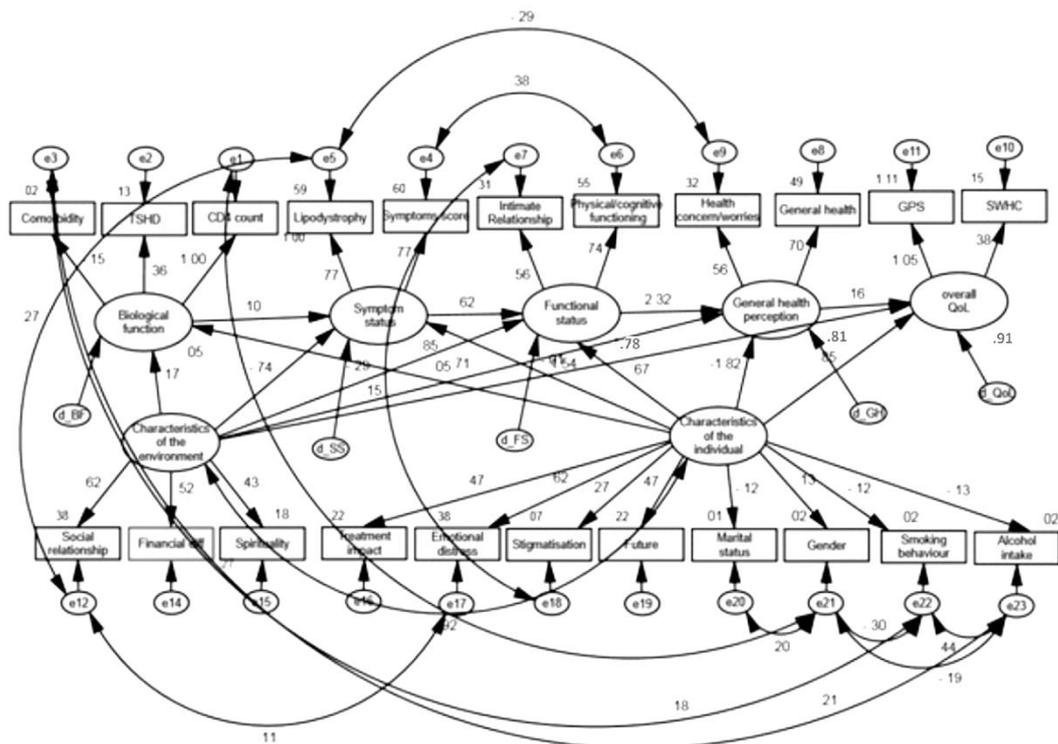
Furthermore, the MI recommend that adding a path between the residual covariance of the error term of spirituality (e15) and stigmatisation (e18) would improve the model by reducing the chi-square statistics by nearly 7.439. This was a reasonable parameter to add because other studies have shown that people with high spiritual beliefs tend to have high risk of stigma (Reyes-Estrada et al 2015, Muturi & An 2010). Step 18 of Table 4.7 shows that the modified model had significantly improved from the previous model ($\chi^2_{\text{D}}(1) = 432.253 - 423.236 = 9.017, p < 0.001$).

After the modification in step 18 in Table 4.7, no further modification was conducted. The final good-fit 7-factor measurement model ($\chi^2_{\text{M}}(177) = 423.236, p < 0.001, \text{CMIN} = 2.391, \text{CFI} = 0.935, \text{RMSEA} = 0.056$ at 90% CI: 0.049 - 0.063, $p = 0.07$) is shown in figure 4.7. The standardised estimates show a reasonable convergent validity among the indicators of each factor. All observed and indicator variables loading were significant at $p < 0.01$. The absolute standardised regression loading varied from 0.05 (marital status \leftarrow characteristics of the individual) to 1.039 (global PROQOL-HIV score \leftarrow overall QoL).

Step 2: The structural model

This section provides the final goodness-of-fit of the model of the structural model. After Post-hoc modification, figure 4.7 have shown that the 7-latent variables measurement with twenty two variables (seven indicators and fifteen observed), the data adequately fit the model. Table 4.8 shows the summary of the Post-hoc modification indices used to achieve model fit of the structural model. The second stage of 2-step modelling was conducted using an adequate measurement model. The reasonably good-fitting 7-factor model was specified again into the revised Wilson and Cleary conceptual model. When all the seven indicators

and fifteen observed variables from the measurement model were included onto to the structural model, the structural model was identified. The results of the standardised solution of the structural model tested are consistent with those of the measurement model. The chi-square of the seven indicators and fifteen observed variables is: $(\chi^2 (195) = 909.027, p < 0.001; CMIN/df = 4.638, CFI = 0.812$ and $RMSEA = 0.091$). The model has been over identified however, the model fit was poor. Furthermore, the estimates output shows that the CR of the variance of error term of d_QoL (disturbance of the latent variable overall QoL) (CR = -0.001, $p = 0.147$) is not statistically significant. The null hypothesis is that the estimate is zero. The absolute value of the CR is below 1.96 (two-tailed). Thus, it is evident that at the 5% level to accept the null hypothesis and it is concluded that the estimate of the parameter is not significantly different from zero. For the remaining estimated parameters in the model, the CR indicates that the estimates are statistically and significant differ from zero. This implies that d_QoL probably not need in the model. Because this test is asymptotically correct, a chi-squared comparison test was conducted to test the hypothesis that $d_qQoL = 0$. A critical value of 3.84 for comparison for a change in a degree of freedom was used by removing a parameter. After constraining $d_qQoL = 0$, the change in chi-square is 2.481, $p = 0.115$ as result of increase of the degree of freedom by 1. This implies that the rise in chi-square is less than critical value of 3.84. The null hypothesis is accepted and therefore, d_qQoL is not significant in the model.



CMIN (χ^2) = 434.204, $p = < 0.001$
df = 184
CMIN/df = 2.36
CFI = 0.934
RMSEA = 0.055 at 90% CI: 0.049 – 0.062, $p = 0.089$

Figure 4.8: The final CFA result of the final seven latent structural model of the revised Wilson and Cleary conceptual model

Table 4.8 Model modification summary of the CFA of the final 7-factor structural model of the revised Wilson and Cleary conceptual model (N = 443)

Model	Model fit			
	χ^2 (<i>p</i> -value)	χ^2 /df	CFI	RMSEA
1. Seven factor CFA, 22 variables	909.027 (<0.001)	4.638	0.812	0.091
2. Constraining d_qQoL = 0	911.508 (<0.001)	4.650	0.812	0.091
3. Added path e22 (smoking behaviour) to e23 (alcohol intake)	806.168 (<0.001)	4.134	0.839	0.084
4. Added path e4 (symptoms score) to e6 (physical and cogn func)	768.956 (<0.001)	3.943	0.849	0.082
5. Added path e21 (gender) to e22 (smoking behaviour)	736.508 (<0.001)	3.769	0.857	0.080
6. Added path e20 (marital status) to e21 (gender)	715.470 (<0.001)	3.707	0.863	0.078
7. Added path e5 (lipodystrophy) to e9 (health concern/worries)	688.126 (<0.001)	3.584	0.869	0.076
8. Added path e12 (social relationship) to e17 (emotional distress)	657.383 (<0.001)	3.442	0.877	0.074
9. Added path e21 (gender) to e23 (alcohol intake)	629.978 (<0.001)	3.316	0.884	0.072
10. Added path e1 (CD4+ count) to e21 (gender)	616.481 (<0.001)	3.262	0.888	0.072
11. Added path Charact o Ind to Charact o Environ	493.069 (<0.001)	2.623	0.920	0.061
12. Added path e5 (lipodystrophy) to e12 (social relationship)	469.624 (<0.001)	2.511	0.926	0.058
13. Added path e7 (intimate relationship) to e18 (stigmatisation)	459.169 (<0.001)	2.469	0.928	0.058
14. Added path e3 (comorbidity) to e23 (alcohol intake)	449.162 (<0.001)	2.428	0.930	0.057
15. Added path e3 (comorbidity) to e22 (smoking behaviour)	434.204 (<0.001)	2.360	0.934	0.055

Note, d_qQoL = variance of the QoL disturbance; Charact o Ind = Characteristics of the individual; Characteristics of the environment; physical and cogn func = physical and cognitive functioning

After constraining the variance d_{qQoL} , the goodness-of-fit of the model was still poor. Therefore, the post-hoc model modification was explored to improve the fit of the 7-factor measurement model. MI results recommendation is consistent with the previous one used recommended in the measurement model, but they differ slightly. Based on the MI recommendations in the structural model, three additional paths were added which were not in the measurement model; these include 1) Added covariance between latent characteristics of the individual and characteristics of the environment. 2) An added path between the residual covariance of the error term of intimate relationship $s(e7)$ and stigmatisation ($e18$). 3) An added path between the residual covariance of the term of emotional distress ($e5$) and social relationship ($e12$).

After adding the thirteenth path as recommended by post-hoc MI, the chi-square statistics of the model fit is $\chi^2_M(184) = 434.204$, $p < 0.001$ which implies that the data did not fit the model. The chi-square statistics cannot be used to test the model fit because of the large sample size and other fit indices suggest that the data fit model adequately: $CMIN/df = 2.36$, $CFI = 0.934$ and $RMSEA = 0.055$ at 90% CI: $0.049 - 0.062$, $p = 0.089$.

Figure 4.8 shows the final CFA and the standardised direct effect estimates of the final 7-factor structural model of the revised Wilson and Cleary conceptual model. Considering the structural path of the revised Wilson and Cleary conceptual model from biological functions \rightarrow symptom status \rightarrow functional status \rightarrow general health perceptions \rightarrow overall QoL, the estimates of the direct effect for each path are statistically significant. The results from the SEM shows that: 1) Biological function is a strong predictor of symptom status (when the biological function goes up by 1 standard deviation, the symptom status goes up by 0.10 ($p = 0.01$) standard deviation). 2) Symptom status is a strong predictor of functional status (when symptom status goes up by 1 standard deviation the functional status goes up by 0.62 ($p = 0.002$) standard deviation). 3) functional status is a strong predictor of general health

perceptions (when functional status goes up by 1 standard deviation the general health perception goes up by 2.32 ($p = 0.008$) standard deviation). General health perception is a strong predictor of the overall QoL (when general health perception goes up by 1 standard deviation the overall QoL goes up by 0.16 ($p = 0.004$) standard deviation).

The estimate for the direct effect of characteristic of the individual is statistically significant on biological function ($\beta = 0.015$, $p = 0.026$), symptom status ($\beta = 0.572$, $p < 0.001$), functional status ($\beta = -0.121$, $p = 0.040$), general health perceptions ($\beta = -0.680$, $p < 0.001$) and overall QoL ($\beta = 0.455$, $p = 0.115$). In addition, the estimate for the direct effect of characteristic of the environment is statistically significant on biological function ($\beta = 0.233$, $p < 0.001$), symptom status ($\beta = 0.314$, $p = 0.048$), functional status ($\beta = 0.236$, $p = 0.035$), general health perceptions ($\beta = -0.352$, $p < 0.001$) and overall QoL ($\beta = 0.143$, $p = 0.01$).

Characteristics of the individual and the characteristics of the environment accounted for 5% of the variance of biological function. Characteristics of the individual, the characteristics of the environment and biological function accounted for 85% of the variance of symptom status. Characteristics of the individual, the characteristics of the environment and symptom status accounted for 78% of the variance of functional status. Characteristics of individual and environment and functional status accounted for 81% of the variance of general health perception. Also, the results showed that 91% of the variance of overall QoL was explained by general health perceptions, characteristics of the individual and characteristics of the environment.

Summary and interpretation of the quantitative findings

A total of 443 PLWHA were surveyed relating to various QoL domains. Both direct and indirect effects between QoL domains in the direction proposed by the revised Wilson and Cleary model were examined using one-way path analysis. Regarding the direct effect of biological function on symptom status, the results showed that participants with higher CD4+ counts had significantly fewer symptoms and less lipodystrophy. Participants with longer time since HIV diagnosis had significantly worse lipodystrophy scores. Also, participants who had no comorbidity had significantly fewer symptoms and lower lipodystrophy scores. This suggests that people with higher CD4+ counts are healthier than those with a lower CD4+ count. Taking ART helps to maintain CD4+ levels, but the downside is that there are long-term side effects such as lipodystrophy which is why this is significantly associated with time since diagnosis. with lesser health concern/worries had a significantly better overall QoL, as measured with the global PROQOL-HIV score. Overall, measures of general health perception (including the variances in measures of biological functions, symptoms status and functional status through the general health perception), characteristics of the individual and environment explained 87.1% of the variance of overall QoL. This suggests that both biological construct (that is, biological function, symptoms status) and social construct (functional status, general perception, characteristics of the individual and environment) have a major impact on QoL.

Results relating to indirect effects in the model showed that biological function had no indirect effect on functional status, general health perception and overall QoL. However, the results showed that there was indirect effect of symptom status on general health perception and overall QoL. Participants with fewer symptoms and less lipodystrophy had significantly better perceived general health and overall QoL (as measured with global PROQOL-HIV score) after controlling for potential effect modifiers. Still on the indirect effect, the results

showed that participants with better functional status measured by physical and cognitive functioning and intimate relationships had a significantly better overall QoL (global PROQOL-HIV score) after controlling for potential effect modifiers. When the result of correlation matrix is compared with the one obtained from the one-way path analysis, it is observed that the reason why a number of the QoL domain of model were not statistically significant is that measures of these domains were weakly and directly correlated to each other as shown in Table 4.4 (correlation matrix). As such, adding effect modifiers into the model to find if the relationship between five endogenous domains of the revised Wilson and Cleary model is mediated by other factors within the model and this resulted in having non-significant effects. In simple terms, the lack of statistical significance in the one-way path analysis between some of the QoL domains is a reflection of lack of variability between these variables as indicated in the weak result from the bivariate correlations analyses.

The results show that older participants significantly had more years since HIV diagnosis and were more troubled with the presence of comorbidity. Also, older participants were significantly more troubled with the presence of lipodystrophy, had significantly lower physical and cognitive functioning, lower intimate relationships and worse overall QoL measured with the global PROQOL-HIV score. The higher presence of lipodystrophy (one of the side effect of prolonged use of ARVs) among the older participants may be due to longer time since HIV diagnosis – this means that they were on ARVs for a longer time than the younger ones. However, the results show that both older and younger participants had similar CD4+ count. This shows both the disadvantages and long-term health gain of ART. It helps to keep the HIV under control, but it is not without a cost and may contribute to a negative impact on their QoL particularly for those taking it long term.

The results show that female participants had significantly higher CD4+ counts and a longer time since HIV diagnosis. However, both male and female participants did not differ.

The results of the direct effect of symptom status on functional status showed that participants with fewer symptoms had significantly better physical and cognitive functioning and intimate relationships. Furthermore, participants with a lower lipodystrophy score had significantly better physical and cognitive functioning and intimate relationships.

The results of the direct effect of functional status on general health perception showed that participants with better physical and cognitive functioning and intimate relationships had significantly better perceived general health. Also, participants with physical and cognitive functioning had significantly less health concern/worries. This suggests that people who either tolerated ART well and did not develop lipodystrophy or had only been on ART for a short time had better functional status. Not surprisingly, this was related to better perceived health and fewer health concerns.

The impact of this can be seen when examining the direct effect of general health perception on overall QoL. The results showed that participants with better perceived general health and significantly in term of their presence of comorbidity, symptoms status, functional status, perceived general health and overall QoL. Higher CD4+ count and longer time since HIV diagnosis among female participants may be because women generally have better health seeking behaviour such as adherence to their ART (Chadambuka et al 2017) and being more likely to present earlier and give consent to voluntary HIV counselling (VCT). VCT tends to be associated with earlier diagnosis followed by initiation on ART (Scanlon & Vreeman 2013). In Nigeria, VCT is part of the routine testing or screening for all pregnant women attending antenatal care as part of the prevention of mother-to-child-transmission of HIV for the HIV prevention and control programme (NACA 2011). The results also show a

significant positive moderate correlation between gender and treatment impact – this may further explain why female participants had higher CD4+ count than their male counterparts.

When the relationship between marital status and the endogenous QoL of domains of the revised Wilson and Cleary model were analysed, the results showed that married participants had a significantly lower presence of comorbidity, better physical and cognitive functioning, better intimate relationships and overall QoL (global PROQOL-HIV score and satisfaction with the health care services). However, married and unmarried participants did not differ significantly in term of the CD4+ count, time since HIV diagnosis, symptom status and perceived general health. This suggests that marriage is either associated with better health and QoL outcomes or that those with better health and QoL are more likely to get married as the data in this study is unable to distinguish temporal order.

Also, the results of the study show that participants who were better educated (having a college or university qualification) had a significantly longer time since HIV diagnosis, better symptoms status and better perceived general health. However, both participants with low and high educational level had similar CD4+ count, presence of comorbidity, health concern/worries and overall QoL. This suggests that those participants who were better educated were more likely to get diagnosed and start ART earlier. This may be as a result of their better understanding of the disease (e.g. mode transmission, complications, benefits of early diagnosis and treatment etc).

Furthermore, participants who smoked tobacco, used alcohol or used both were significantly more troubled with the presence of comorbidity. This implies that tobacco smoking increased the risk of comorbidity such as bronchitis among participants and also, alcohol increased the risk of some forms of end-organ diseases such as hepatitis, these are common

forms of comorbidity seen among PLWHA. However, tobacco smoking behaviour, alcohol use and illicit drug use were not significantly related to symptoms status, functional status, general health and overall QoL of the participants. This may be because few participants reported engaging in these forms of risky health behaviours and most participants in the study were relatively clinically stable because they were all taking ART.

Participants who had better treatment impact, lower emotional distress and with less perceived HIV-related stigma had a significantly better QoL measured with the global PROQOL-HIV score. This is to be expected as good adherence to ART without experiencing side effects mean that it brings all the advantages and none of the disadvantages associated with ART.

The results also show that participants with better social relationships had significantly better symptoms status, better intimate relationships and overall QoL. This indicates that good social support, especially from family members, might have helped the participants with better social relationships to adhere to ART which reduces symptoms and helped them to cope with the disease. Further, participants with less financial difficulties and those with higher spiritual beliefs (an important coping strategy for some) had significantly better overall QoL. This suggests that participants with higher incomes could afford to provide for themselves and their family which, in turn, helped them to have better QoL. Also, participants with higher spiritual beliefs tend to easily accept their diagnosis by seeing it as an act of God.

In these results, it is observed that many of the predictors of the global PROQOL-HIV score (as a measure of overall QoL) form part of this measure so of course, they will predict global PROQOL-HIV to a certain extent. For example, treatment, future, stigmatisation and emotional distress all contribute to the overall PROQOL-HIV score and therefore, not surprisingly, they were all significantly related to it. Given this, it is unknown whether

stigmatisation, treatment impact emotional distress etc would be significantly related to overall QoL in this sample of PLWHA in North-eastern Nigeria if independent measures were used. This is an important limitation of this study and it is discussed further in Chapter 6.

SEM was used to examine the fourteen simultaneous relationships (see Figure 4.1) between the various QoL domains as depicted by the revised Wilson and Cleary model and also to assess the goodness of fit of the model. The results show that the relationships between the four endogenous latent variables were statistically significant, that is 1) between biological function and symptom status (when the biological function goes up by 1 standard deviation, the symptom status goes up by 0.10 ($p = 0.01$) standard deviation). 2) between symptom status and functional status (when symptom status goes up by 1 standard deviation the functional status goes up by 0.62 ($p = 0.002$) standard deviation. 3) between functional status and general health perceptions (when functional status goes up by 1 standard deviation the general health perception goes up by 2.32 ($p = 0.008$) standard deviation). Between general health perception and overall QoL (when general health perception goes up by 1 standard deviation the overall QoL goes up by 0.16 ($p = 0.004$) standard deviation). Further, the relationships between characteristics of the individual and biological function, symptom status and functional status were statistically significant. The relationships between characteristics of the environment and biological function, symptom status, functional status were also statistically significant. However, there was no significant relationship between characteristics of the individual overall QoL as well as the relationships between characteristics of the environment, and overall QoL was not statistically significant. Characteristics of the individual and the characteristics of the environment accounted for 5% of the variance of biological function. Characteristics of the individual, the characteristics of the environment and biological function accounted for 85%

of the variance of symptom status. Characteristics of the individual, the characteristics of the environment and symptom status accounted for the nearly 87% of the variance of functional status. Characteristics of individual and environment and functional status accounted for 81% of the variance of general health perception. Also, the result showed that 91% variance of overall QoL was explained by general health perceptions, characteristics of the individual and characteristics of the environment. This suggests that characteristics of individual and environment are strongly associated to biological function, symptoms status, functional status and general health perception and that it is through the perception of health that they are associated to overall QoL. Also, through general health; biological function, symptoms status and functional status were strongly associated with overall QoL. Therefore, the findings indicate that health is key to overall QoL and that other influences such as gender, age, educational status, spirituality and social relationship etc have a much lower impact.

Finally, 2-step SEM was conducted to assess the goodness-of-fit of the revised Wilson and Cleary model. Seven indicators and fifteen observed variables from the structural model showed that data from North-eastern Nigeria adequately fit the 7-factor structural model of the revised Wilson and Cleary conceptual model (CMIN/df = 2.36, CFI = 0.934 and RMSWA = 0.055, 90% CI: 0.049 – 0.062; $p = 0.087$). While attempting to obtain goodness-of-fit of the measurement and structural models, several modifications were needed (that is, the omission of several measured variables, and the addition of correlated measurement errors). In this study, the modification indices suggested that there may be correlations between the measurement errors of indicators of nonadjacent latent variables in the proposed fully mediated model, that is, the relationship between error terms of spirituality and stigma. This signifies the flexible nature of the revised Wilson and Cleary model as there is no standard guideline for variable selection for the model and the model developers

allow the absence of relationships between nonadjacent levels to be added (Wilson & Cleary 1995). This inherent flexibility of the revised Wilson and Cleary conceptual model makes it suitable for application in any population and setting. Moreover, the adequate model fit in the present study is an indication of its relevance in a low resource setting like North-eastern Nigeria.

The next chapter presents the findings of the qualitative study.

Chapter Five

Results of the qualitative study

Introduction

The previous chapter provided the findings of the quantitative study. This current chapter provides the findings of the qualitative data analysis that explored the impact of HIV on QoL of PLHWA receiving ART including their live experience living with the disease in Maiduguri North-eastern Nigeria. The findings will be used to provide the meaning of the associations that emerged from the quantitative results and to provide a deeper understanding of the impact of HIV on QoL (research objective 4 on page 102). Also, the impact of political conflict on health, HIV care and QoL was provided in this chapter (research objective 6 on page 102).

Fourteen participants (6 males and 8 females) with age ranged from 25 years to 65 years participated in the qualitative phase of the study. The average age and time since HIV diagnosis of the participants were 43.92 years and 4.71 years respectively. Table 5.1 shows sample characteristics of the fourteen participants interviewed. The findings of the qualitative data also provided a deeper understanding of the lived experience of PLWHA in a conflict setting.

Framework analysis was used to analyse the qualitative data; this is detailed in Chapter three on page 139 - 141 (qualitative data analysis section). Initially, ten codes were generated, but during the indexing phase, seventeen sub-codes emerged. Any data without a clear meaning was excluded. Charts were then developed to contain distilled summaries of views of the participants. After careful assessment of the seventeen sub-codes generated, those with a similar meaning were merged to form themes. Eight broader themes emerged were generated. Following further examination and through discussion with supervisors

who familiarised themselves with the data, these were further reduced to six themes and 5 sub-themes. These included QoL is more than being free of disease; impact of HIV on well-being, impact of insecurity on health, HIV care and QoL; stigmatisation; coping strategies, and playing with ART. These six broad themes were then mapped to identify any associations. Figure 5.1 is a flowchart showing a summary of how the themes were generated.

Table 5.1: Sample characteristics of the qualitative participants (N = 14)

Participants	Code	Brief description of the participants	Gender	Age (years)	Marital Status	Religion	TSHD (year)	PROQOL-HIV score	Remarks
Participants 1	P1	Lives at Hausari ward, Maiduguri with her parents. Hausari ward is a low-middle income area around the city centre of Maiduguri. This is a commercial area and is 2 miles away from the hospital where the study was conducted. In 2012, the area has been affected by the insurgency as the insurgents tried to loot.	Female	45	Widowed	Muslim	3	44.7	Low
Participants 2	P2	Lives at Pompomari Housing estate, Maiduguri, with her husband. Pompomari is a middle income area and is within the city of Maiduguri. It is nearly 5 miles away from the hospital. This area was relatively peaceful at the time of the insurgency. Residents were mostly civil servants.	Female	55	Married	Christian	4	72.2	High
Participants 3	P3	Lives at Ngomari ward, Maiduguri on her own. Ngomari is a low income settlement in Maiduguri 10 miles away from the hospital. This area was affected by the insurgency at the time when insecurity was intense before the government brought it under control.	Female	62	Married	Muslim	5	55.4	Moderate
Participants 4	P4	She is from Mongono town (50 miles away from Maiduguri). Mongono is affected by the insurgency. Currently she lives at Bulunkutu ward in Maiduguri with relations as an IDP. Bulunkutu ward is a low income area and is nearly 10 miles away from the hospital. In 2012, Bulunkutu was partly affected by the insurgency.	Female	25	Divorced	Muslim	3	40.5	Low
Participants 5	P5	Lives at Sabon Layi ward in Maiduguri with her husband. Sobon layi is a low-middle income area situated half-a-mile from the hospital. The area is not affected by the insurgency.	Male	60	Married	Muslim	9	45.1	Low
Participants 6	P6	He is from Mainok a suburb of Maiduguri but now lives in Maiduguri with relations as an IDP. Mainok is 20 miles away from the city of Maiduguri. This area was mostly affected by the insurgency.	Male	52	Divorcee	Muslim	10	62.9	High

Note: IDP- internally displace persons; TSHD- time since HIV diagnosis

Table 5.1: Sample characteristic of the qualitative participants...continued (N = 14)

Participants	Code	Brief description of the participants	Gender	Age (years)	Marital Status	Religion	TSHD (year)	PROQOL-HIV score	Remarks
Participants 7	P7	Lives at Shehuri ward in Maiduguri with her husband. It is a low income area located nearly a mile and half from the hospital. It was relative safe because it is close to the Emir's Palace.	Female	31	Married	Muslim	1	45.1	Low
Participants 8	P8	Lives at Ngomari Airport (near Maiduguri international airport) in Maiduguri with her children and brothers. Ngomari Airport is a low-middle income area. It is 10 miles away from the hospital. The area was relative safe because of its proximity to the airport which is well secured by the security forces.	Female	40	Married	Muslim	2	66.1	High
Participants 9	P9	He is from Bama town (3rd largest town in Borno state and 70 miles from Maiduguri) but now lives at London Ciki ward in Maiduguri with the brother in-law as an IDP. It is a low income area and is half-a-mile away from the hospital.	Male	65	Divorce	Muslim	2	70.2	High
Participants 10	P10	She is from Madagali town (150 miles away from Maiduguri) in Adamawa state but now lives in Maiduguri with relatives as an IDP. Adamawa state shares border with Borno state.	Female	40	Married	Christian	2	58.9	Moderate
Participants 11	P11	Lives alone at State Low-cost housing Estate in Maiduguri. It is a middle income settlement and is approximately 1.5 mile away from the hospital. The area is safe	Male	34	Single	Christian	6	60	High
Participants 12	P12	Lives at Jimtilo a suburb of Maiduguri with a friend. Jimtilo is a low income linear settlement 20 miles away from the city of Maiduguri. In 2011 the area was affected by the insurgency but at the time of the study peace has been restored.	Female	35	Single	Muslim	5	53	Low
Participants 13	P13	Lives at Pompomari ward in Maiduguri with the family. Pompomari is a middle income area and it is nearly 5 miles away from the hospital. This area was relatively peaceful at the time of the insurgency. Residents were mostly civil servants.	Male	40	Married	Christian	5	56.4	Moderate
Participants 14	P14	Live at Lamusla ward in Maiduguri with his parents. Lamusla ward is low-middle income area. It was affected by the insurgency and is 2 miles away from the hospital.	Male	45	Widower	Muslim	9	47	Low

Note: IDP- internally displace persons; TSHD- time since HIV diagnosis

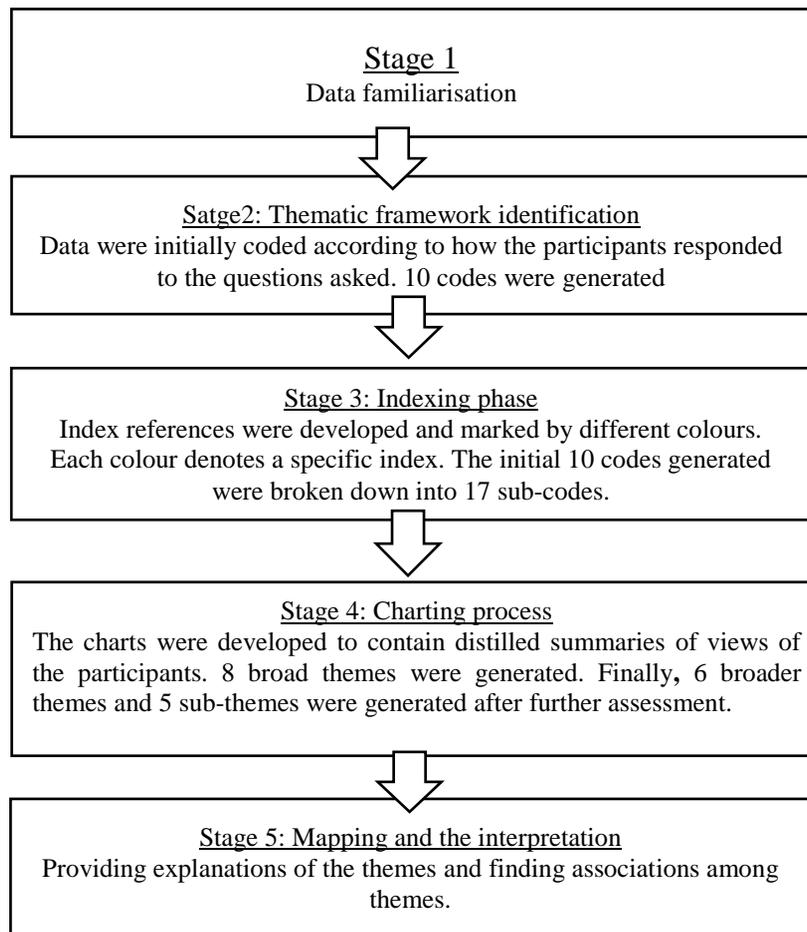


Figure 5.1: A flowchart showing the summary how the themes were generated

QoL is more than being free of disease

This theme described how participants understood the term QoL. Participants described QoL in terms of happiness and general well-being impacted by having money, psychological well-being, good health, spiritually committed, good social cohesion, healthy eating and security. Nine of the 14 participants interviewed defined QoL in a way comparable to the WHO definition of health as “a state of complete physical, mental and social well-being and not merely absence of disease or infirmity” (Mutabazi-Mwesigire et al 2014 p:3-4). One 52-year-old man (P6) receiving HIV care remarked that “*QoL is to live healthy, physically strong, and be upright psychologically...able to eat well and have good people around you especially the ones that care for you in every circumstance you find yourself. I forgot another important thing about QoL is to be financially buoyant.*” A 40-year-old man (P13) said that to him QoL is being happy, your importance in the family and ability to forget whatever type of illness you are

suffering from whether it is cancer or HIV as long as you are on medication and compliant is the key thing in life. But for a 45-year-old man (P14) “*QoL is to live a disease free life.*” According to this participant (P14), it is devastating living with a chronic disease such as HIV because it reduces productivity, function and physical appearance which are vital to QoL. The 45-year-old man continued by saying that:

“...this HIV...always weakens my body... [get] fatigue easily and...makes me sleep a lot. I don't have the strength to do my daily activities. Before...this HIV, I'm rich, I don't suffer like now...it's pathetic. HIV has made me to become poor. It doesn't let me go about doing my business like before...today you are sick and tomorrow you are well...I was very light in complexion but...now I lost weight, rashes and black spots all over my body and I have darkened seriously...some people...don't even recognise me easily these days...”

Many of the interviewees stressed the importance of having enough money as the basis of their well-being and hence a good QoL. On a general note, the participants were modest in their expectations. Often, they talked about the importance of having enough money to pay their bills such as buying food. Also, some said having enough was important because they do not want to worry about money any time should an unexpected expense comes up. For instance, 2 participants viewed QoL as “*...have some money with you to take care of yourself and your family*” (A 45-year-old man (P14)) and “*If you've money most of your problem will be solved and you'll be less dependent on people. You will do a lot without bothering anyone, I believe that's QoL*” (A 62-year-old woman (P3)). Further, participants especially the females stressed financial empowerment as means of good QoL. These female participants linked their finance to their ability to enjoy life and to be able to pay bills without seeking financial help from anybody.

Happiness was mentioned by many of the participants as an indicator of good QoL. They remarked that financial well-being, good social interaction, good family relation and good personal and family health were factors mentioned as sources of happiness. Being happy all the time was stressed as an essential thing to having a good QoL. The happiness expressed by the participant as the critical aspect of QoL was when they have their family and friends around that are supportive, these give them joy and also a good sense of well-being. According to some

participants “*QoL is to be healthy and happy all the time...*” (A 25-year-old woman (P4)) [with] “*...your lovely family around you*” (A 45-year-old man (P14)).

Good social relationships were also described by some of the participants as an important thing to having a good QoL. One 34-year-old woman (P11) remarked the importance of family in life especially children, for example, she said that “*QoL means to have your children [and] maintain good health...*” Others participants went further to say that apart from having good social relationships with family members it was also essential to have a good rapport with people they associate with in their daily lives. This form of social relationship plays a significant role in their well-being. A 62-year-old woman (P3) stated that “*QoL is to...have good family and friends around you that are kind and supportive...*”

Living in sound mental health was a concern among four participants. These participants described QoL as being “*...mentally sound...*,” (A 31-year-old woman (P7)), “*...be good psychologically*” (A 45-year-old man (P14)) and “*...be upright psychologically...*” (A 52-year-old man (P6)). Having a life without stress or worries was seen as means of attaining an emotional stability and hence good well-being. Participants reiterated that their actions and lives were influenced by their attitude, personality and mental outlook characteristics. Positive impacts of good mental health on QoL expressed by the interviewees were being optimistic and having a positive attitude rather than worrying about life or feeling unhappy with themselves.

Overwhelmingly, having sound physical well-being was also described by some participants as a way of useful life. That is the ability of an individual to maintain an efficient physical life functioning. To these participants, the ability to be physically active to carry out their daily activities efficiently and independently, participate in sporting activities and be able to work to earn enough money to take care of themselves and family were critical to their well-being and good QoL. Across the board, QoL was described as “*...be physically active and look good...*” (female, 62 years (P3); male, 45 years (P14)); “*...be physically strong...*” (male, 52 years (P6)); “*...be physically sound, nice and beautiful...*” (female, 31 years (P7)); and “*...the way you live...and be physically active in sporting activities your take in*” (male, 34 years (P11)).

Two participants interviewed linked QoL to their spiritual well-being. Both participants were Muslims. They believed that having spiritual cleanness and holiness in their daily lives were crucial for having good QoL. One 31-year-old woman (P7) described QoL as “...to be *spiritually clean*”. Furthermore, one 65-year-old man (P9) said that participation in religious activities (for example, daily prayers, supplication and other rituals) and being thoughtful of life after death gave him joy and better QoL. He had this to say: “*QoL is for a man to have some activities of religion and [be] thinking of hereafter not of this world*”.

Among few of the participants interviewed, they stressed that living in a secured neighbourhood was imperative, and it was described as a way of better QoL. These participants expressed that life was worthless when there is no peace in their lived environment. They perceived that insecurity has put fear in their lives because of the unlawful loss of lives and properties and displacement. Two participants described QoL concerning insecurity as: “*QoL is...to live in a crime free environment.*” (A 31-year-old woman (P7))

“*QoL is to ...live in well secured environment not like what we are experiencing during this Boko Haram security challenge*”. (A 45-year-old man (P14))

The findings from this study showed that the meaning of QoL described by the participants did not differ substantially among participants. However, more male participants defined QoL as being physically active and having stable income while more female participants defined QoL by body image (that is, looking cute and beautiful) despite their differences in age and PROQOL-HIV score. Further, more participants with low PROQOL-HIV score defined QoL by having sound mental and psychological well-being.

Impact of HIV on well-being

This theme explored how living with HIV influenced the general well-being of the participants. It also describes how HIV infection impacted on the different aspects that the participants said were important when defining QoL in section 1.1 above. The aspects of well-being reported by the participants were the social relationships with family and friends, intimate relationship, physical functioning, cognitive and mental well-being, finance including work.

Impact of HIV on social relationships with family and friends

This subtheme describes the importance of family life and how HIV affected the social relationships between the participants and their family and friends. Two participants stressed that family life was essential to them.

“Things that I like more importantly in life today is to get married...and regain my family life back to normal like before- that’s me, a wife and my children living under the same roof”. (A 45-year-old man (P14))

“Family life is the most important thing that matters to me now.” (A 31-year-old woman (P7))

As some participants stressed the importance of family life, but others said that the relationship with their family became sour since their HIV diagnosis. For instance, one participant had this to say: *“Even relatives and some friends who are supposed to know, accommodate or support you in a difficult situation like this but they tend to distance themselves from you”* (A 45-year-old woman (P14)).

One 35 years old woman (P12) spoke about the desire of connection with others. For this participant, all her life was occupied with how to improve her well-being, and she was not able to socialise like before her HIV diagnosis. The participant had this to say:

“before I hung around with a lot of people and I socialize with everybody I met in life- I go anywhere without thinking of anything but now I don’t do all these things- I keep myself busy looking for ways on how to I suppose to maintain a good health or improve my health”.

Irrespective of gender, some participants stressed that their HIV infection had ruined their family life and had brought an end to their marriage. For example, one 25 years old woman (P4) said that *“I was married before my diagnosis but my 4 years marriage ended 2 years ago as a result of this HIV”*. Two female participants said that their HIV diagnosis had made them experience domestic violence. For instance, one 31-year-old woman (P7) remarked that:

“...since when my doctor told me I have HIV...me and husband fight all the time. On three occasions he hit me badly just because I asked whether he has HIV. I left and his relations pleaded and return me back.”

These participants believed that they were infected by their spouses and they were not getting the required support needed. Lack of trust and lack of being sincere to these participants by their spouses left them in agony. As a result, it caused disharmony and poor social relationship within the family.

Death of family members was another negative social impact HIV as expressed by one participant. The one participant (male, 45 years (P14)) was worried that HIV had caused the death of his wife and children. The participant remarked that:

“HIV infection has affected my family life badly- I lost my wife and two children as a result of this disease. These people were so dear to me. May their gentle souls rest in peace...”

However, six participants interviewed said their living with HIV did not affect the relationship with their family and friends. These participants said that their relationships remained unchanged despite the fact that their HIV status was known to the family and friends. Some said that they receive a lot of support and encouragement from their family and friends since their diagnosis.

“All my 5 children know about my situation, they’re all very supportive from onset to date...I have a cordial relationship with my family and friends despite they’re aware of my status- they always give me moral and spiritual support and some even give me money to buy good food [and] also to buy medicines [medications] which sometime is prescribed outside the ARVs” (A 62-year-old woman (P3)).

“The happy thing is my family and friends relate with me cordially despite the knowing I have HIV- these guys always encourage me to stay strong and to be optimistic living with HIV” (A 52-year-old man (P6)).

The good social relationships expressed by older participants was probably because in Nigerian culture parents look after their children, in turn, the children are required to look after their parents in their old age irrespective of the situation the parents found themselves.

Some participants said that their family and friends encouraged them to be strong and this gave them a sense of belonging and adhere to their ART; this affects their QoL positively. For

instance, a 45-year old woman (P1) said that: “...my 20 years old daughter always makes sure I don't miss ARVs and she takes care of me.” Other participants said that:

“...one of my close friend that knows about my HIV status gives me money and sometime buys me food supplementary medications like multivitamin and mineral capsule when he comes to visit me... If you get this type of friend around you, your life will always be good.” (A 45-year-old male participant (P14))

“...my husband always support me and encourage me to be taking my drugs [ARVs] regularly [...] if you don't play with your drugs [ARVs], you'll not be coughing or passing shit [diarrhea] all the time or TB [tuberculosis].” (A 40-year-old female participant (P8))

Impact of HIV on intimate relationship

This subtheme describes how living with HIV affected the intimate relationships of the participants, hence QoL. Maintaining a healthy sex life was an essential aspect of having good QoL among the participants. Five participants said that their sexual desire considerably reduced. For some, the lack of desire was because of the thought that they acquired the HIV sexually. According to a 31-year-old married woman (P7) “my sexual desire has slightly reduced. If you know you contracted the disease [HIV] through sexual intercourse, you tend to avoid it or take you mind off it...”. Similarly, some participants felt that their lack of sexual desire was because of lack of strength. One 45 years old woman (P1) said that “After all, how can you think of having sex when you are sick- that is, you sick today and you are well tomorrow. Is it not when you have strength you can have sex? You have to be physically strong and you have rest of mind before you can think of sex in your life.”

Also, some married female participants said they were less keen on sex because they were worried about infecting their HIV negative sexual partners (husbands). According to these participants, their physician advised to practice safe sex, but their husbands also declined to it. This kind of unhealthy sex practice was a cause of concern to these participants. For example, 2 participants remarked that:

“...my husband...[is] negative since we discovered I have HIV 5 year ago. We were all counselled at the HIV treatment centre...to [be] engaging on protected sex but he always refuse- I don't want infect him [...]. This makes me have less interest in sex. I

always tell him that he shouldn't risk his health since...we can...still have sex with the use of condom but he always say[s] he doesn't enjoy that..." (A 55-year old female participant (P2))

"This HIV has made me to be keeping away from sex- before my HIV diagnosis I use to have sex but now I don't care about it- I always been thinking that I'm HIV positive. I don't want to have sex because I don't want somebody to become infected with HIV. My sexual desire is still normal but I always tried to make sex out of my mind" (A 35-year old female participant (P12)).

Also, a divorcee 25-year old woman (P4) also said that she does not want to infect anybody and because of this, she avoided getting married again. She expressed that *"...because of my HIV status...I don't want to ruin anybody's life...for this reason I decided to abstain and avoid marrying again after my divorce"*. Similarly, one 45-year old (P1) also said that:

"I don't like to be close to men since the death of my late husband 4 years ago. I am just 45 years old and now I have some men that approach for marriage, they know that I am a widow but I always say to them I am still mourning my late hubby just to scare them away. Please where or how do I start? Should I marry and go and start having sex without telling the person I marry my situation...I think that is a cheat. I think probably this is why [I am less keen] about sex, in fact I do not have the urge at all. HIV is terrible."

However, some participants reported that their sexual desire was still normal despite their HIV seropositive status. For instance, one 34 years old male participant (P11) said that *"well, HIV has not affected my...sexual behaviour."* Other participants said that their sexual desire was still normal and were much less worried having sex because they were counselled at the HIV Care Centre on how to practice safe sex. One 40-year-old woman (P10) had this to say: *"my sexual behaviour is not affected only that since my diagnosis I don't like to have sex without condom as I was told by the doctors at the HIV clinic"*.

Evidently, this result shows that young female participants and those with low PROQOL-HIV score reported having problems with their intimate relationships and the primary reasons was afraid of infecting potential sexual partner or having thought that they contracted the disease

through sex. Older female participants reported that abstinence from sex was because of socio-cultural beliefs that when a person grows older, the person should abstain from sex.

Impact of HIV on physical functioning

This subtheme described how HIV infection had affected the physical well-being of the participants. Participants stressed the importance of maintaining independence to their well-being. For example, for some participants after the HIV diagnosis, they find it difficult to do their laundry or walk a long distance without being tired. Two participants expressed that:

“My life quality is not good as it used to be, I can’t do a lot of things like before because I get tired easily. I depend on people to do my laundry [and] I can’t walk long distance...” (A 45-year-old woman (P1))

“For the past one year my physical well-being has dropped I get tired easily and I lost some body weight but now I’m slightly getting better” (A 34-year-old woman (P11)).

Half of the participants interviewed highlighted that their HIV related symptoms such as easy fatigue, generalised body weakness and body wasting were affecting their ability to do daily activities effectively. For example, two participants said that:

“I have lost considerable body weight...My worry with this my HIV infection is it always weakens my body- I feel fatigued always, it makes me sleep a lot. I don’t have the strength to do my daily activities like walking a distance” (A 45-year-old man (P14)).

“The negative aspect living with HIV is you see somebody with a red lips and have a skinny or small skull and one kind body shape that you don’t know them with it before and you see [feel] weak always {and} not active like before the HIV infection” (A 35-year-old woman (P12)).

Female participants were more worried about the change in their body figure or image such as having body wasting and body rashes and spots. For example, one 35-year-old woman (P35) remarked *“my worry is that I have become slim- my body wasn’t like this before”*. This change of body figure had made one of the female participants to change the way she dresses by wearing a long dress to the body. The participant said that *“things are not like before- I liked to*

wear skirts and blouse before but I now choose to wear a long dress to cover my skinny and black spotty legs to avoid people talking” (A 31-year-old woman (P7)).

However, for some participants, their HIV diagnosis did not affect their physical functioning. These participants said that they could do their routine daily activities efficiently. One 62 years old woman (P3) said that *“I’m physically ...good. I...tidy my house and room or cook my local food- children of nowadays don’t know how to cook some of these local food. I enjoy them more than these jellof rice, pasta, and fry-fry”*. One of the interviewee (female, 55-year-old (P2)) even said she participates in sporting activity. This participant said that *“I play football regularly to keep myself physically fit...though [this] may sound crazy but it’s working for me”*.

These findings suggest that HIV infection affects physical well-being of the participants. However, male participants were more concern about their physical functioning as they were worried about frequent body weakness and easy fatigue that affect their day-to-day activities such as going out to work to earn money to take care of their family. Not that the female participants too were not worried about body weakness and fatigue but also they were more worried about their body image (that is, how they look) despite their differences in age and PROQOL-HIV score.

Impact of HIV on mental well-being and cognitive functioning

This subtheme described how HIV affects the mental and cognitive well-being of the participants. One 62-year-old woman (P3) reported that she was psychologically not disturbed by her HIV status. Her reason was that of the good relationship with the people around her. The 62-year-old woman (P3) said *“I’m...mentally good...people around me don’t see me as someone who has HIV”*. However, for some participants, their HIV positive status was their nightmare. These participants said that thinking about being HIV positive was making them feel sad and depressed. Two participants said that:

“HIV is a shameful disease it always makes me sad, worried, and even depresses me at time if I remember it” (A 55-year-old woman (P2)).

“If I...remember this HIV, it makes sad and sometime it depresses me...” (A 31-year-old woman (P7)).

The negative impact that HIV has on the psychological well-being of these participants was the negative perception the society attached to HIV infection. This was according to one 52-year-old man (P6). He remarked that *“The society still sees HIV infected person as irresponsible, that’s my concern.”* Other participants felt emotionally distressed the thought anytime about their HIV status and looking at how their body figure had changed as a result of symptoms such as weight loss or body rashes and inability to efficiently do their daily activities like before they became HIV positive. For instance, two participants had this to say:

“...I always feel sad, anxious and sometimes a bit irritated when I remember I have HIV...Before I became positive [HIV] I don’t have these rashes and I wear size 14 but now I look at how this disease disfigures me. People will start to suspect that you have HIV and this affects you psychologically”. (A 25-year-old female participant (P4))

“Anytime I thing of this HIV, I always feel depressed. You be feeling depressed all the time and not have a good life quality, you know...mentally you can’t be normal”. (A 45-year old man (P12))

Irrespective of gender, time since HIV diagnosis and PROQOL-HIV global score, two young participants said that their HIV infection had made them get confused easily and sometimes they do not remember things happening around them. These poor cognitive functions mentioned by the participants were a major concern to them affecting their well-being negatively. Two participants had this to say:

“...I...forget things easily now unlike before my HIV diagnosis. Before if I discussed something with you or keep something I will not forget easily but now if I do something or keep something then I will later come back in a short time and say what is this-and-that” (A 35-year-old woman (P12)).

“...these days I don’t know what’s wrong with me because I do forget things easily and sometime I get confused over issues but the confusion matter is now resolved. This type of thing affects me mentally; it saddens me you know” (A 45-year-old man (P14)).

The findings suggest that impact of HIV infection on mental and cognitive well-being was more defined by the time since HIV diagnosis and PROQOL-HIV global score. The finding showed that participants who were newly diagnosed with HIV stressed having poor

psychological well-being and emotionally distressed and this was similar to those with low to moderate PROQOL-HIV global score. The poor cognitive function emphasised by the two participants may be attributed to the cerebral effect of HIV (this is usually seen when the HIV infection has disseminated to the brain) or cerebral manifestations of the ART adverse on the PLWHA (Pandya et al 2005).

Impact of HIV on finance and work

This subtheme highlighted the impact of living with HIV had on the work and the income of the participants. The ability to work and earn enough money to pay bills was a concern to some of the participants. According to one 45-year-old woman (P1), her primary concern was how to be healthy to work and earn money to provide for her children. This woman had this to say:

“My main concern is for my two children and the situation has worsened since my sickness started. I can’t work as hard as before to be able to provide enough for them, but how can I do other than to try to be strong -I don’t want them to suffer”. (A 45 years old woman (P1))

Some participants were worried about lack of strength to work regularly to earn enough money. For example, a 35-year-old woman (P12) said that her income had dropped because of lack of strength to work regularly. The participant expressed that:

“If you have the strength to work then you will have a steady income or it increases but anytime you didn’t go to work due to sickness your income will definitely... drop- like now I stay almost 6 weeks without doing my restaurant business from that time to-date there’s no any extra income coming to me- I only depend on my monthly salary because I teach in a primary school”.

Similarly, one 45-year-old man (P14) said his HIV status had made him poor. He was worried that he lost all his possession following HIV diagnosis. The 45-year-old man (P14) stressed that:

“Before I have this HIV, I’m rich, I don’t suffer like now, I owned 3 cars and I owned a poultry farm for my family consumption but now in the last 3 -5 years I lost all these fortunes. Now I use a cab or ‘Keke NAPEP’ [commercial tricycle] to go about my little remaining business. It’s pathetic; HIV has made me to become poor. It doesn’t let me go

about doing my business like before I was HIV positive- today you are sick and tomorrow you are well. This type of thing affects my finances”.

However, for some especially female participants said that their HIV status did not affect their work and finance because they were full-time housewives. They reiterated that their husbands take care of them. Moreover, for the elderly female participants, they reported that their children provide for them. For example, below are the views of some of these participants:

“My status doesn’t affect my income because my husband takes care of me. He gives me money to go hospital, buy food and solve my other financial problems” (A 40-year-old woman (P8)).

“I don’t have any financial problem all my kids are grown up, they give me a lot of money to spend which sometime I give money to my grandchildren when they visit me and I help others that I see in difficulties...” (A 62-year-old woman (P3)).

It is worthy to note having dependent children was disadvantageous to some participants because they were worried about how to earn money to cater for these children. On the contrary, having adult children had a positive impact on the finances of some of the participants. This is not a surprise because in Nigeria it is believed that parents take care of their children when they are young while the children are expected to take care of the parents when they are old.

Impact of stigmatisation and disclosure on QoL

This theme described how perceived stigma affected the QoL of the participants. Three types of stigma were reported by the participants. These forms include actual (real) stigma, internalised stigma and fear of being stigmatised. This theme also described how some participants were able to manage the stigma.

Actual stigma

Participants reported that they were being stigmatised after they were diagnosed with HIV. They were troubled that the stigma comes from their family, friends or people they relate to their daily life. The collective means of stigmatisation mentioned by participants include

gossip and avoidance from the people around them. For example, one participant had this to say:

“My problem living with HIV is when people know you are HIV positive they will be running away from or they will not like to associate with you in any way. It’s disturbing, it makes you feel bad about it and sometime it’s depressing. Some people will even stigmatise eating with you but they will not openly say why they are showing such bad behaviour. Even to give me food or drugs they wear gloves. There was a time I heard one of my brothers gossiping about my illness. You know the way you are treated speaks volumes about the nature of your issue or circumstance. The perception that you are a potential source of infection is always there and it resonates in the way people deal with you” (A 45-year-old woman (P14)).

Some participants experienced stigma but others perceived that they were being stigmatised while there was no stigma shown to them. Two participants remarked that:

“...members of my family- I meant everybody...kind of stigmatise at you and that scares you” (A 34-year-old male participant (P11))

“It’s depressing living with HIV, when people know about your status they stigmatise at you- as some will not want to eat with you or a share toilet with you. It’s really a bad situation to experience that a horrifying moment in life- worst of all you experiencing such avoidance from your own person.” (A 25-year-old female participant (P4))

Some participants reported no sense of any form of stigma. Two women said that the people around them were supportive and they had a cordial relationship despite their HIV status. These women had this to say:

“There are some people that know I have HIV but they still bear with me- ...I have never experience any sign of stigma from them- we live in a good mood, we help each other all the time” (A 35-year-old woman (P12)).

“...people around me as don’t see me one who has HIV.” (A 62-year-old woman (P3))

Internalised stigma/self-stigma

Self-stigma has been reported by two participants. They said that their HIV diagnosis had led them to stigmatise themselves leading to social withdrawal and low self-esteem. One 25-year-old the female participant (P4) said that she sometimes avoids going to social gatherings or occasions (for example, naming or wedding ceremonies) because of

the belief that people may see her and talk about her HIV status. Another participant (A 45-year-old man (P14)) has an internalised feelings of shame, guilt and he blamed himself due to the negative social judgment of his HIV positive status.

“This HIV make you guilty and shame especially when you had several sex before. You’ve avoid anytime that will make your HIV status reveal any how...one needs to maintain low profile when associating with people”. (A 45-year-old man (P14))

Fear of being stigmatised

Participants were also bothered about what their family, friends and neighbours thought of them. They feared discrimination, stigma and getting into trouble with family members. Also, participants were also being fearful of how people will speculate how they had been infected with HIV by judging them wrongly. These participants tended not to disclose their HIV status because the society they live in still attaches shame to HIV infection. The common reason was that most people in their society still believe that the only mode of HIV transmission is through heterosexual sex and unless you are promiscuous you will not be infected with HIV infection. A 55-year-old woman (P2) expressed her displeasure that she has never had sex in her life until after she got married and admitted that her husband infected her with HIV. According to the participant (P2), she maintained her HIV status undisclosed because of fear of being stigmatised. The participant had this to say:

“Since my HIV diagnosis, none of my family member knows about my disease even my mum. I don’t want to get in trouble with the people around me. HIV is a shameful disease it always makes me sad, worried, and even depresses me at times if I remember it. It’s honestly sad, you don’t know anything [engaged in sex] until you got married to somebody who was cheating on you and he ended up bringing this shameless disease”.

For some participants, they dislike disclosing their HIV status in any way and were anxious about being ousted by the presence of ill health or being seen attending the HIV care centre. This was important to them to maintain healthy well-being. Anxiety about disclosure to parents and children was considered most distressful. One 25-year-old female (P4) participant had this to say: *“...now that my child is growing I don’t want him to know my situation- I don’t know*

how he'll feel about it if he knows". Therefore, keeping a secret of their HIV status has helped them cope and live peacefully in the society as stated by one 35-year-old woman. She had this to say:

"I don't want my family to know I have HIV- presently my family don't know about my status especially my mother and my child because I'm not married- I have been divorced almost 10 years ago...Living secretly with HIV helps to cope and live with the society because if people know that you have HIV they will start saying this-and-that and that will make you ashamed of living a life even though you are taking the drugs [ARVs] ..." (A 35-year-old woman (P12))

For some participants they were not only disturbed by the social stigma they directly faced but the stigma was even extended to their family members, for example, their children who are not infected with the HIV are afraid that that situation will affect their academic performance and hinder a good social relationship with their friends. A 25-year-old woman (P4) affirmed that:

"...if people should know about it [my HIV status] ...some may stigmatise at him [son] that will affect his performance at school and his relationship with his peers. He's just an innocent young boy- it is appalling having HIV, it is really awful".

Managing stigma

The negative perception of living with HIV in the community where the study was conducted persist. These forms of rude behaviours from the people have made some of the participants to avoid being recognised. A 55-year-old Christian woman (P2) said that she always comes to the ARV centre very early in the morning and also wears headscarf and face veil as a disguise to avoid being recognised by others when she comes to collect her ART medications. The woman remarked:

"Since I have been diagnosed of this disease I have a specific cloths and shoe and I always wear face veil to cover my face to come to the hospital for my drugs- I don't want to be recognised ... I also ...come to the hospital very early in the morning ...for my routine visit to this HIV treatment at the teaching hospital- I don't want to meet people that know me, the result is that if people see you here in this HIV clinic they will start to ask you questions and then before you know it is all over the town and gossip starts".

Another 31-year-old female (P7) participant said that life was not the same after HIV diagnosis. This participant said that changes in body image such as body wasting and black spots on the body had made change her way of dressing. The participant had this to say:

“Things are not like before- I like to wear skirt and blouse before but I choose to be wearing long dress to cover my skinny and black spotty legs to avoid talks from people”.

As some participants downplay their identity by changing the way they previously dressed before their HIV diagnosis in managing stigma. However, others were optimistically living with the HIV infection. For example, a 52-year-old male (P6) participant seemed to have come to terms with his illness by being more optimistic living with HIV. According to him “...*why will you stigmatise at yourself? If you want to survive this HIV sicknesses...don't stigmatise yourself and you'd be confident and believe in yourself. May be I'm an old baba [dad] that's why I think that way but that's life. This life is too short whether we like it or not we'll all die one day- so why should I disturb myself*”. Further, some participant decided that the best option is to disclose their HIV status to deal with the stigma that is faced by some PLWHA and this had also helped them live a better life. To overcome the stigma these participants disclosed their HIV status both to family members and people around them. For example, 2 participants had this to say:

“I disclose to people that I am HIV positive even my children know about it...If you did not fight stigma in this HIV thing, the stigma will definitely finish you. That is why in this HIV clinic some people still hide to visit the clinic, cover their faces or even hide to take their drugs [ARV] ”. (A 45-year-old woman (P1))

“I disclose my status but it's astonishing to see some people hiding themselves...you see ladies wearing head scarf or veil to cover their faces and some that don't cover will not like to look at you in your eyes- It's really sickening” (A 52-year-old man (P6))

A 65-year-old man (P9) said that he was able to manage stigma by regularly taking his ARVs because since he began the ART, all his symptoms disappeared to extend that people were even doubting if he is living with HIV.

“I best way to avoid stigma is to take your drug as directed by the doctors. The HIV medicine [ARVs] makes you feel well and heal all these HIV symptoms. Before some

people gossip that I have HIV and even avoided me but since I began this HIV treatment I became very well. Now lots of people are saying that it's just a rumour earlier that I have HIV."

Coping strategies of living with HIV infection

This theme described several strategies used by participants to cope living with HIV. Participants interviewed described that their QoL was influenced by how they had coped with the HIV infection. Majority of participants when newly diagnosed felt so hopeless and emphasised the importance to think positively. All the participants described different coping strategies to deal with their situations after being diagnosed with HIV infection to continue to carry on with life positively. Spiritual beliefs and values were the dominant coping strategy by the participants, as 9 of the 14 participants stressed that regular prayers (supplications) and submitting all their problems with God were their most coping strategies. They attached much importance to their spiritual beliefs. Participants reiterated that through the power of prayers, seeing their diagnosis as a destiny from God and leaving their situation in the hand of God played a major role in keeping them healthy, fit and forgot about being HIV positive. The use of spiritual beliefs as coping strategy described by these participant cut across all the spectra (that is, there was no difference in term of sex, age, time since HIV diagnosis, PROQOL-HIV score and place of living). Three participants put it like this:

"...you know if you have faith and pray as well it helps, and nothing pass God's power {nothing is greater than the power of God}- if not we would have all been dead and it is even the prayer that helps me to forget that I am HIV positive which ...always keep me strong and forget about it. Now I only remember the disease when it's time for my hospital visit to collect my drugs". (A 45-year-old woman (P1))

"If you remember that you're HIV positive it makes you go crazy but with prayers you tend to forget about it, it helped me a lot and that's what is keeping most of us alive". (A 25-year-old woman (P4))

"Being HIV positive I leave everything to God Almighty, He's the sustainer. My spiritual believe helps me cope with my HIV status- and that's my strength". (A 45-year-old man (P14))

Some participants had a positive interpretation of their situation by comparing themselves with others which allowed them to increase their self-esteem, confidence and hold a more positive future outlook on life. One 31-year-old woman (P7) said that: *“...when you see other patients at the clinic who are in a very bad state and compare them with myself I feel happy and thankful to God and even forget I have HIV.”*

Healthy eating was another coping strategy mentioned by participants. They highlighted the vital role of the healthy diet as advised by their healthcare providers at the HIV care centre. Participants were passionate that healthy eating such as fruits and vegetables had positively improved their well-being and had helped them cope with the burdens of HIV and ARV. The issue relating to healthy eating was highlighted by female participants irrespective of age. Two participants remarked that:

“The food I eat is also helping me a lot to cope with this HIV.” (A 35-year-old woman (P12))

“...at the HIV clinic we're been advised to eat a well balance diet especially those that boost the immune system like fruits, vegetable, beans, fish and milk...I improve on my dieting...I regularly eat more fruits and vegetable and foods that are very rich in protein, vitamins and minerals. All these... good food are seriously working- see me now unless I disclose to you that I have this disease [HIV] you'll not know.” (A 62-year-old woman (P3))

Despite the participants who were receiving HIV care specifically ART, they emphasised that eating good food improved their QoL. Some participants compared their previous health and that once after they improved their diet found that healthy eating substantially improved their well-being. For example, peace of mind, weight gain and reduced burdened of ARVs such as stomach upset and dizziness were some of the benefits reported to have been achieved as a result of healthy eating. One 34-year-old man (P11) described QoL as *“...how you take care of yourself is by the kind of food you eat”* [that is] *...take [ing] care of life [and] eating good food. You know eating good food helps not to be having dizziness and stomach pain...before when I take the medicine [ARVs] before eating, I feek dizzy and some like I want to throw-up...”*

For one 40-year-old man (P13) reading culture was taken to cope with the illness. The participant said *“...I read my books a lot...unless I come to the hospital for my HIV drugs I*

don't discover [remember] that I have HIV infection.” While another participant (female, 25 years old (P4)) used regular exercise to cope with HIV status. The participant said she derives pleasure by going to the gym because of the interaction with other people over there. The participant had this to say:

“...I...registered with a nearby gym for regular exercise, I enjoy it and it makes me happy. I get to mix with different people where you share ideas and thoughts- all these help me cope with my HIV status.” (A 40-year-old woman (P10))

Furthermore, one 34-year old participant (male, P11) said that regular playing of football had a remarkable positive impact in coping with his HIV. He had this to say:

“I play fooball regularly...I enjoy it; this makes me forget about my HIV. [...] playing gives me energy and cope as well.”

In this analysis, it is observed that younger participants are those mostly reported using physical activity as coping strategy. This is probably because the younger participants are more physically fit and older tend to like isolation.

Playing with antiretroviral therapy (ART)

This theme describes the decision-making about ART uptake and the effects of ARVs on the QoL of the participants. Readiness for regular intake of ART by the participants is of major importance in the process of antiretroviral decision-making. Participants describe the dialectical process of decision-making with a focus on interactions with others. The critical issues that informed decision-making among participants interviewed in accepting ART include life perspective, therapy beliefs and hopes, health perspectives including illness beliefs. Also, the data analysis shows that healthcare providers play a major role in treatment decisions. In other words, surrogate markers (CD4+ count) and presence of HIV related symptoms, doubts about personal necessity, concerns about adverse effects of ART, QoL issues, distrust of ART and the attitude toward death were all associated with the decision adhere to ART or not. Almost all participants used the term “playing with drugs” to describe their informed decision about ART uptake. The term was usually used by the healthcare providers (physicians, nurses, pharmacist

etc) at the HIV clinic to warn participants about the importance of regular and prompt intake of ART.

Additionally, the theme also describes the impact of ART on the well-being of the participants. For many of the participants, adhering to the ARVs is vital to their well-being. These participants were very optimistic in taking the ARVs regularly. For example, one participant said: *“When I was diagnosed I got enrolled and since [then] I don’t play with my HIV drugs. I take them regularly”* (A 52-year-old man (P6)). Another participant (male, 34 years old (P11)) went on further to say that he was comfortable taking the ARVs as far he can live. The 34-year-old man remarked that *“...I’m taking my medicine [ARVs] regularly and this is what I want to be doing with rest of my life.”* Even with the trouble of having to take the ARVs daily still participants were very enthusiastic in their routine medication. One 40-year-old man (P13) said *“...I am feeling comfortable taking my mineral capsule [ARVs]. The major thing is taking your drugs regularly. The good thing is that since I discover that I have HIV infection, I started my medicine [ARVs] -steadily I’m managing my life.”*

The positive attitude exhibited by participants toward adherence to ARVs was because of the counselling received during the ARVs initiation. Participants said they were advised to take their medication regularly to maintain good health, hence well-being. One 31-year-old woman (P7) said that *“I had an appointment with the doctors at the HIV clinic to commence me on ARVs. Before the doctor placed me on the drugs, I was counselled that HIV doesn’t kill and I can live a normal life if I take my HIV medicine regularly.”* In addition to the counselling received, the reason for good adherence for some participant was the horrible experience of deteriorating health due to their previous non-adherence. Two participants had this to say:

“There was a time I played with my HIV medicine, that time I became seriously ill...I was vomiting and passing ...watery stool anyhow, I had fever and mouth thrush... {and} ...my CD4+ counts seriously dropped [...] I was counselled again on the need to adhere to my drugs [ARVs] and since then I resumed taking my HIV medicine with all sense of seriousness.” (A 45-year-old man (P14))

“There was a time I stopped even taking my ARVs...my CD4+ counts dropped seriously –that was from 394 to less than 200. I experienced a lot of health problems- I lost a

significant body weight, rashes all over my body and itched me badly that even stopped me from sleeping.” (A 25-year-old woman (P4))

In addition, regular taking of the ARVs was because it helped in preventing the chance of having HIV related opportunistic diseases. For instance, one 62-year-old woman (P3) expressed that:

“If you play with your medication [ARVs] is like playing with your life...the HIV drugs makes you live long and also make you out of the trouble of opportunistic sickness as long as you adhere to it [...] you can't afford to be missing your drugs anyhow, we're been counselled on the importance of good adherence to the ARVs at the HIV clinic that we'd not joke with them if we want to live a healthy or normal.”

Similarly, for some participants, the reason for not playing with the ARVs was the fear that their health will deteriorate if they did not adhere to it. For example, two participants had this to say:

“If you play with your drugs before you realise your CD4+ count drops and HIV related symptoms like fatigue, fever, and a bad cough will start to manifest or you put yourself at risk of falling ill.” (A 52-year-old man (P6))

“When you missed taking your drugs at normal time you supposed to, you will start to fall sick or your CD4+ count tends to drop and some symptoms of the HIV appear.” (A 34-year-old man (P11))

Half of the participants interviewed had reported a significant satisfaction and improvement of their health status with taking ARVs. Two participants said that the ARVs were the main source of their longevity and survival. For example, one 45-year-old woman (P1) expressed that *“...this medicine is really helping...if not one would have by now...”* Further, the ARVs were also seen as a lifeline and life cannot be meaningful with them according to a 55-year-old woman (P2). She said that *“...this HIV drugs is {are something} we cannot do without them- they are our lifeline.”*

Some participants were so positive that the ARVs had helped to maintain good health. These promising effects of the ARVs reported were the disappearance of HIV related symptoms such as weight loss, diarrhoea, body rashes, cough and persistent fever as well as getting relieved of HIV related opportunistic diseases. Three participants had this to say:

“The HIV drugs help...I added weight, I don't have a cough, fever or body rashes like before. I'm looking better now since I started taking the HIV drugs.” (A 31-year-old woman (P7))

“First time I feel so many illnesses like infection and severe headache, diarrhoea, and some symptoms of malaria and typhoid fever et cetera, et cetera. But later...when I decided {started}...take{ing} the medicine [ARVs] gradually-gradually all the symptoms disappeared...even people said that it was just a rumour supplied by people he's completely not infected {that I am infected with HIV}” (A 65-year-old man (P9))

“The good thing is the HIV drugs make you out of the trouble of opportunistic sickness as long as you adhere to it...{they} are seriously working.” (A 62-year-old woman (P3))

Because of how healthy the 62-year-old woman believed to be, the elderly woman went on further to say that *“...since...I started these HIV drugs...see me now unless I disclose to you that I have this disease [HIV] you'll not know.”* The immediate positive changes observed by the participants in their health after ARVs initiation, one 40-year-old man (P13) gave the ARVs a nick name and saw them as a food. He said:

“...my life [health] is improving since I started taking my drugs [ARVs]...I called it mineral capsules. It...serves as food. I am feeling comfortable taking my mineral capsule. The good thing is that since I discover that I have HIV infection, I started my medicine- steadily I'm managing my life.”

The benefits the participants derived from the ARVs had led some of them to say that they will be troubled if the HIV prevention and treatment was to be stopped in Nigeria as was being alleged. Their concern was that life is going to be difficult for some of them because they cannot afford to buy the HIV medication. One participant expressed that:

“My fear is the rumour that the free HIV drugs are not going to continue for the reason that the funding partners are going to stop assisting but if that happen many people living with HIV will start dying rampantly like before. It will be hard for many to afford the drugs [ARVs] that you need to be taking for rest of your life- life is going to be too expensive again, you will buy food, drugs, and paying school fees. We pray that shouldn't happen”. (A 60-year-old man (P5))

Despite some participants strictly adhering to the ARVs as advised by the counsellor at the HIV care Centre and the positive impact of the ARVs in improving their well-being including

increased longevity, some participants showed a poor attitude towards taking the medication regularly. The reason for the poor compliance was because of the size of the ARVs. According to a 45-year-old woman (P1) “...*I hate the drugs- I find it difficult to swallow...feel like throwing up and they make sleep too much. ...I use to play with my drugs and at a point in time I even stopped taking it emmm! I nearly die woooo.*” The ill health experienced as a result of poor adherence to ARVs was a cause of concern to two participants. They said most of the time you see some patients at the clinic seriously ill because they were playing with their medication. According to these participants:

“Sometime you see patients that are very weak and don’t even have the strength to sit on the chairs provided at the reception area while waiting to be seen by a doctor at the HIV clinic. I feel bad for them but sometime some of these HIV patients play with not taking the drugs regularly that’s why they face these sorts of challenges” (A 55-year-old woman (P2)).

“At the HIV clinic I see people that play with their medication, I’m telling you they aren’t finding it easy as you see them looking very weak, vomiting profusely, stooling [diarrhoea] and their skin full of ugly rashes” (A 62-year-old woman (P3)).

For some participants, the poor compliance to their medication was because of the ARVs related side effects and also worries of having to take the ARVs daily. A 31-year-old woman said that (P7) “...*occasionally I get stomach ache, nausea or slight dizziness when I take the medicine [ARVs] if my stomach isn’t full enough. The HIV drugs also weaken me and it makes me sleep too much. It’s worrisome that I’ve to over feed before I take my drugs.*” One 62-year-old woman remarked that “...*having to take my HIV drugs every day is a main impact of HIV disease in my life.*” Similarly, another negative impact of ARVs highlight was getting worn out (developing resistant) with the medication. According to a 25-year-old (P4) “*the hope living with HIV is narrowed even if with the ARVs you get worn out with the drugs having to take them every day.*” Furthermore, some participants were worried about how their life was tight around or controlled by the ARVs. For instance, one 45-year-old woman (P1) said that “*HIV is a kinda a disease that controls your life always...I hate the drugs- I find it difficult to swallow the big blue and sometime they make me feel like throwing up and they make sleep too much...at a point in time I even stopped taking it...*”

Impact of insecurity on HIV care, health and QoL

This theme highlighted how access to HIV care, Health and QoL of the participants were affected by insecurity. Almost all the participants mentioned that insecurity had immensely affected their health, HIV care and QoL negatively. Majority of the participants reported that sometime the insurgency had affected their access to healthcare that has either stopped them from going for follow-up or stopped them from collecting ARVs prescription. Participants said that the poor access to HIV care was caused by either an attack by the insurgents, imposed a curfew or a road blockade by the security agents on duty. The road blockade and curfew usually happened whenever there was an attack by the insurgents. Initially, 24 to 48 hours curfew will be imposed then it then relaxed by restricting only vehicular movement. The curfew usually continued until the situation became under control. In some situation where participants live in areas very far from the hospital can find it difficult to access their HIV care regularly. For example, one 40-year old woman who lives Ngomari Airport with her family which is about 10 miles away from the hospital remarked that *“the insecurity is seriously affecting my life, you can’t move around like before [because]...there’s no road. It’s a very hard time we are facing. You don’t have rest of mind”*. Another 35-year old woman who lives at Jimtilo (a suburb 20 miles away from the city of Maiduguri had this to say: *“[GOSH]! This insurgency is affecting my HIV treatment because sometime I want to come to the hospital for my HIV drugs they will say there’s a curfew and I’m from a far place. I can’t walk to the hospital”*.

Because these participants live with a chronic disease (HIV infection), some of them feared that their health would worsen by the reappearance of HIV-related symptoms due to inconsistency with medication (ARVs) and fear of insurgent-related killing which affects them mentally. Despite the insecurity faced by these participants most of them showed commitment to their HIV medications. Three participants had this to say:

“The insecurity has very much affected my health in the sense that sometime when you want to go out for... drugs picking you discover that the road has been blocked because something has happened somewhere leading to the hospital- you’ve to go back and when you go back you still have the fear you will miss your drugs for some days- one or two things will happen to you- I meant symptoms of the HIV will start to manifest. And

you go back to your state of poor health or sickness. It has really affected us badly". (A 34-year-old man (P11))

"The insurgency has been affecting my HIV treatment and hospital visit negatively. Accessibility to the hospital to have your ARVs when you are running out of stock or when you are ill is sometime not viable- perhaps either due to road closure or there's a curfew in town and that time your sickness worsen." (A 25-year-old woman (P4)).

"Sometime we that have this HIV can't go to hospital to collect drugs or you're sick you want to see a doctor but no road. Roads may be closed or there is a curfew- you know it's not advisable to be running out of drug for us living with HIV unless you want to die young or live hopelessly because you are always sick." (A 31-year-old woman (P7)).

However, for two male participants, the insurgent did not affect their access to HIV care. For example, one 65-year-old man (P9) said it was due to his proximity to the hospital where the care was being provided, and he had this to say:

"the insecurity didn't affect my HIV treatment because where I'm living is not very far away from the University Teaching Hospital- I come to take my medicine [ARVs] frequently and go and use it."

And for one 45-year-old man (P14) it was due to importance he attached to the ARVs and remarked that

"I am lucky since the beginning of this insecurity challenge I have not missed my hospital appointment to see a doctor or to pick up my HIV drugs. I take my medication seriously now, that's my life line."

The good thing was that even at the time when the insurgency was very intense the University of Maiduguri Teaching Hospital was still functional. The hospital and its environs are always guarded by proper arm law enforcement officers and soldiers and serve at the first point of call to treat victims of the insurgency. The participants acknowledged that food insecurity and destruction of livelihoods such as businesses, homes and social cohesion that had in practice before the insecurity had affected their well-being. For example, one 25-year-old female (P4) participant said that *"...the insurgency...makes your sickness worsen. It's a scary situation we are in, your mind [is] ...not...at rest and is psychologically disturbing"*. Some participants said that coping with living with HIV infection was much more comfortable and had less impact on

their QoL than coping with the insecurity. For instance, one 35-year-old woman (P12) described her situation as:

“...this insurgency troubles me even more than the HIV infection. The HIV has a place where I will go and take my routine medication and recover myself but Boko Haram insurgency has destroyed my life in several ways, for example- they stop my business and I can't live with the feeling that I'm a human being. If I think of them I will even forget that I have the HIV. They trouble us a lot- we can't even get food to eat. You have the money and you want buy something but you can't go out due to imposed curfew in town. At a time, {you} even...struggle to earn money...- life is too tough. [...] This Boko Haram insecurity has taken us far back- it has brought poverty into the society.”

In general, some of the participants acknowledged that the unrest had a definite negative impact on their access to HIV care, almost all the participants said the insecurity had impacted negatively on their QoL. The destruction of the family structure, loss of lives and properties (for example, homes), restriction of movement and destruction of business caused by the insecurity had affected their QoL negatively. Some participants could not hide their emotions because all their possessions were lost. For example, one 40-year-old woman (P10) said that:

The insecurity has affected my...QoL...badly. Before we lived in our own house but now we are forced out. All what you had through hard work is destroyed within a few minutes. Thank God we have relatives that shelter us but it's not easy living outside your own house...Sometime you live with hunger- it's a serious concern, often time, you're mentally sick.

The relationships between the themes and QoL

Figure 6.2 is a diagram showing a relationship between the emerged themes and QoL. Framework data analysis was used to analyse the data. In the analysis, six broad themes were developed. The themes developed included QoL is more than being free of disease; impact of HIV on well-being; stigmatisation; coping strategies; playing with ART and impact of insecurity on health, HIV care and QoL.

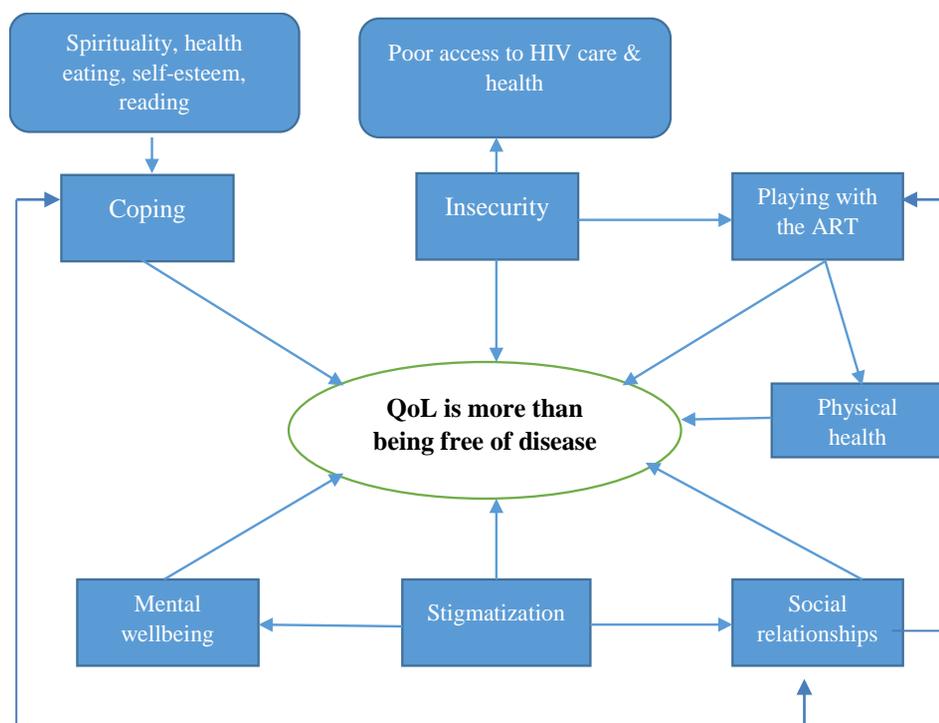


Figure 5.2: A Diagrammatic illustration of the relationships between the emerged themes

All the emerging themes had a direct impact on the QoL of the participants. Additionally, it was observed that there is a relationship between some of the themes. Physical health was not the only one of the factors affecting QoL and not one of the most important ones. For instance, most participants remarked that change in body figure and unnecessary body rashes due to HIV related symptoms remarkably affected their social relationship and mental well-being including their overall QoL negatively. Easy fatigue and lack of strength to carry out daily activities were said to be affecting their mental health, finances and intimate relationship negatively.

Sex and age were found to have a direct impact on finance and social relationship. The results of the qualitative data analysis showed that married female participants were less worried about their finances as most of them received financial support from their husbands when compared with their male counterparts who were the breadwinners of their family. Furthermore, older female participants have shown to be less worried about finances because of the social support they said to get from children.

Issues related to stigma seemed to have a much bigger impact than the physical health on QoL. This could be because the impact of ARVs in controlling the severity of the illness is well

acknowledged by the participants. As such, most of the participants are reasonably well most of the time. The findings of this data analysis show that stigmatisation had a direct negative impact on mental well-being, intimate relationship and social relationships and this had a detrimental effect on their QoL.

The playing with ART theme shows the tension that participants have with taking regular medication and the desire to keep physically well. The tension associated with the regular taking of ARVs was seen as a daily reminder of their HIV status and had shown to have a negative impact on the mental well-being of the participants. The findings also show that social stigma had a negative impact on adherence to ART as some participants hide to take their routine medications or chose specific times to go for follow-up at the HIV care Centre. Besides, the negative impact of stigma on adherence to ART, however, social relationships had a significant positive impact on adherence to ART. As such, some participants in this study remarked that good social relationships with a family member such as children or spouses and support (inform of reminder) from these family members had helped them to adhere to their ART.

The insecurity is a threat to accessing ART and therefore, has particular salience for PLWHA in North-eastern Nigeria. Spiritual believes, healthy eating, self-esteem, reading and regular exercise are different strategies employed by the participants to cope with the illness. These coping strategies have an impact positively on their QoL. Coping strategies such as increased self-esteem and exercise have a significant impact in improving social relationships among participants, as it helped them to interact freely with other members of the society socially, – while for some good social relationships with family and friends had a profound positive impact on coping with HIV.

The next chapter is the Discussion chapter (Chapter six). In chapter 6, both quantitative and qualitative results will be merged, and the qualitative results will be used to provide a better understanding of the quantitative results. Also, key findings of the research studies were discussed within the context of HIV care and support in North-eastern Nigeria.

Chapter Six

Discussion

Introduction

This study aimed to examine the key determinants of HRQoL of PLWHA receiving ART and to examine the relationship between the components of the revised Wilson and Cleary conceptual HRQoL model. Further, this study aimed to explore the lived experience of PLWHA to provide a deeper understanding of how HIV impacts on QoL. Chapters four and five presented and discussed the quantitative and qualitative results respectively. Therefore, this chapter merges the quantitative and qualitative results to address the study aim of using the qualitative data to understand better the reason for the associations identified in the quantitative analysis. This chapter compares the critical findings of the quantitative and qualitative studies with the existing literature and also discusses the meaning of the results within the context of HIV care and support in North-eastern Nigeria. Furthermore, strengths and weaknesses of the study are discussed. Finally, this chapter provides the recommendations for policy and further research and the conclusion of the study.

Sociodemographic characteristics and quality of life

The sample of this study were mainly young persons aged between 18 – 40 years old and about two-thirds were female reflecting the composition of PLWHA in Nigeria (NACA 2011, FMoH 2011). A number of demographic factors contributed to a diminished perception of HRQoL among the respondents of the interviews and the questionnaires. Notably, older participants reported significantly lower functional status (intimate relationship and physical and cognitive functioning) and overall QoL. This result agrees with the findings of previous cross-sectional studies from Southern Nigeria (Akinboro et al 2014) and Croatia (Belak Kovacevic et al 2006). The lower functional status reported by, the older participants may be attributed to muscle atrophy, reduced muscle strength and agility as well as a decline in sex hormones that are associated with ageing (Cunningham et al 2015). Also, a lower frequency of social contacts and the lower level of physical activity associated with old age may play a role in the decline of the functional status of the older participants (Sibbritt et al 2007). In Nigeria, older persons tend to

retire from active service (for example employment/working, farming or business/trading etc) because of the sociocultural belief that when you grow old, your children take care you. Although a distinctive prominent socio-cultural feature in Nigeria is for family members to take care of their parents in old age, it is not clear if this social support system can compensate for the decline in functional status noted among older PLWHA, to improve HRQoL of older PLWHA in Nigeria.

Highly educated (those with college/university education) participants were less troubled by symptoms and lipodystrophy despite reporting a significantly longer time since HIV diagnosis, possibly reflecting their better understanding of living with HIV and better adherence to treatment, reinforced by positive treatment outcomes. The reason for having a significantly longer time since HIV diagnosis among highly educated participants compared to less educated counterparts could be that those with higher education were more aware of the need to check their health status and were more likely to be diagnosed earlier compared to those with low education. However, this finding was contrary to that reported in a previous cross-sectional study in the US which aimed to assess the relationship between education and risk of HIV infection among African-American (Hasnain et al 2007). The US study found PLWHA with lower educational attainment (that is those with less than high school education) were 58% more likely to have a significantly longer time since diagnosis compared to those with high school and above level of education. Perhaps, the discrepant findings from the two studies is a reflection of the different patterns of influence of educational attainment on risky sexual behaviours and health practices between people in Nigeria and the US. It seems while risky sexual practices that could predispose to HIV infection are more common among the educated people in Nigeria, these may be more common among people with lower education in the US.

Based on my anecdotal experience as a clinician in a tertiary health facility in Nigeria since 2005, most of the people that were diagnosed with HIV were highly educated (having college diplomas or university degrees). This is partly consistent with the association between higher educational level and longer time since HIV diagnosis found in this current study. In Nigeria like other parts of the world, persons with higher education are more likely to have a better job

and higher income, and to engage in better health behaviour (Brännulund et al 2013, Fletcher & Frivold 2009). For instance, in the early 2000s, it was the educated that could afford to come to the hospital no matter how far the distance to seek treatment because at that time the University of Maiduguri Teaching Hospital was the only HIV centre in entire North-eastern Nigeria. Perhaps, people with lower educational level and of lower income status in North-eastern Nigeria would only come to get tested and treated when ARVs are available at the tertiary hospitals. Arguably, most PLWHA especially the less educated and low income could have died unknowingly of HIV/AIDS-related complications in most peripheral hospitals (health centres, primary health care centres) due to lack of expertise and resources for diagnosing HIV.

This study found that unmarried participants had a significantly higher presence of comorbidity. This may be due to poor or a lack of social support from family members such as husband or wife to adhere to treatment. This was suggested by the qualitative results – for instance, one of the married female participants remarked that her husband encouraged her to adhere to her ART and she felt that a good attitude toward ART helped to minimise the risk of having comorbidity such as TB.

Nevertheless, regardless of gender and marital status, overall, most participants in this study reported having higher symptoms, diminished general health and overall QoL. This suggests that physical discomfort, diminished health and reduced QoL are dominants domains of health-related QoL that could be directly attributable to HIV infection among PLWHA in North-eastern Nigeria. This finding corroborates previous studies in Southern Nigeria (Folasire et al 2014, Odili et al 2011, Fatiregun et al 2009).

This study found that participants with higher CD4+ count had a significantly lower symptoms status (measured by symptoms score and lipodystrophy). This result supports previous studies in the US who also found that high CD4+ count is significantly related to fewer symptoms (Sousa & Kwok 2006, Henderson et al 2012, Safren et al 2012). Increase in years of time since HIV diagnosis was associated with the presence of lipodystrophy (lower lipodystrophy score), in line with the findings of Miller et al (2003) in Australia. This may be attributed to the prolonged use of ART because lipodystrophy has been reported in several studies as one of the

adverse effects of long-term use of ART (da Cunha et al 2015, Guaraldi et al 2014, Brown & Glesby 2011). The average time since HIV diagnosis of the participants was 6 years, and PLWHA in Nigeria initiates ART as soon as possible after diagnosis if they meet the WHO guidelines (NACA 2010).

Participants with fewer symptoms and less lipodystrophy had significantly better physical and cognitive functioning, which is similar to findings in studies conducted in the US using the Wilson and Cleary model to assess QoL in PLWHA (Ryu et al 2009, Sousa & Kwok et al 2006). As reported in earlier studies (Nokes et al 2011, Sousa & Kwok 2006), participants with better functional status (measured by physical and cognitive functioning as well as the intimate relationship) had significantly better perceived general health. Consistent with a previous cross-sectional study from South Africa (Phaladze et al 2005), participants with better perceived general health had a significantly better overall QoL as measured by the global PROQOL-HIV score.

Meaning of quality of life

PROQOL-HIV score was used to assess quality of life. The mean subscale scores ranged from 18.88 (stigmatisation) to 85.11 (satisfaction with the healthcare services). The mean of the overall QoL score (global PROQOL mean score) is 56.42. The mean values of stigmatisation and overall QoL are lower compared to those reported in Hermann and colleagues (2013) study that used PROQOL-HIV questionnaire to assess the impact of HIV-related stigma and physical symptoms on HRQoL in Australia. This disparity is probably because of the difference in where the two studies were conducted. For example, in Nigeria HIV infection is still highly stigmatised (Folasire et al 2014, 2012, Adedimeji et al 2010). Furthermore, lower overall QoL may be because the current study was conducted in a politically unstable environment (that is, conflict area) and differences in socioeconomic status. Nigeria is a low middle-income country while Australia is a high-income country; so QoL in Nigeria is likely and expected to be lower than in Australia.

The narratives of the participants alluded to the concept of “QoL is more than being free of disease”. Very few participants defined QoL as being solely related to HIV. A possible reason

for the relatively limited impact of HIV on their definition of QoL is that all the participants interviewed in this study were taking ARVs and were relatively 'well' and asymptomatic. Factors such as being happy at all time, having financial independence and good family support were major indicators of QoL reported by the participants. These findings are consistent with the results reported in previous studies that have examined the impact of HIV on PLWHA receiving ART in other low-income countries such as Uganda (Mutabazi-Mwesigire et al 2014) and high-income countries such as Australia (Herrmann et al 2013).

The findings of the qualitative study showed that the meaning of QoL was in line with four aspects of QoL proposed by Veenhoven (2000 p.4). These aspects include 'inner appreciation of life, external utility of life, life ability of the individual and liveability of the environment'. Participants described the prevailing economic circumstances such as having enough money as being important for QoL, –this narrative suggested the concept of liveability of the environment. Both male and female participants stressed that having a stable income was essential to them for having good QoL. Participants viewed that their QoL was associated with their perceived value in society and factors such as the ability to provide for their families especially children. This finding is consistent with previous qualitative studies from Southern Nigeria (Adedimeji et al 2010) and China (Ho et al 2010) who also found that having a steady income among PLWHA was important to support family members.

The findings also showed that QoL is defined as life being good for something more than itself, which alludes to Veenhoven's external utility of life. For instance, some participants (especially married male participants) stressed that QoL was defined by their perceived usefulness in the society and how one was able to provide for their family. The reason for why married male participants related QoL with the ability to provide for the family may be because of the cultural practice in North-eastern Nigeria that it is the sole responsibility of a husband/father to provide basic needs of life (food, shelter and clothing) for their family.

Life ability of the individual is considered as to how one can cope with life situations. Participants in this study described feelings of a stigma that sometimes resulted in non-disclosure of their HIV status. Female participants were more vocal about feelings of shame

related to their illness. However, these participants reported that they were in good health and living a normal life. These findings reflect the sociocultural and religious context of the setting where the study was conducted. North-eastern Nigeria is highly religious, patriarchal and morally sensitive to issues relating to sexuality. As such, HIV is considered, albeit wrongly, as a disease of sexual immorality and remains highly stigmatised. Thus, women may likely be more ashamed about their HIV status than men in this setting. Despite this stigma and shame, PLWHA in North-eastern Nigeria may compensate and quickly adjust to their reality based on their deep religious conviction and faith to accept their situation in life as an “act of God”. Hence, the ability of the participants in the present study to report they were in good health and living a normal life.

The inner appreciation of life aspect of Veemhoven’s typology relates to the participants’ definition of QoL as being happy and devotion to religious/spiritual beliefs at all times. In this study linking happiness with QoL had an interesting gender dimension. Based on the definition of happiness and well-being as being related to the ‘presence of positive affect and absence of negative affect’ (Bishop et al 2011 p.2), male participants described happiness merely as the presence of positive affect, whereas female participants portrayed it in term of associating with family and friends. This gender differences in the concept of happiness reflects the needs for gender-specific strategies when delivering interventions to promote QoL among PLWHA in North-eastern Nigeria. However, there was no gender or age difference in relating QoL and religious/spiritual beliefs. This may be because in North-eastern Nigeria religious/spiritual beliefs play a vital role in shaping people’s way of life.

Symptoms and impact on functioning

The quantitative results found that participants with fewer symptoms and less lipodystrophy had significantly better physical and cognitive functioning. This finding corroborates with the qualitative results reported under the sub-themes “impact of HIV on physical functioning” and “impact of HIV on mental well-being and cognitive functioning”. Some of the participants reported that HIV did not affect their physical health. These participants said that the reason behind their healthy physical functioning was because they were asymptomatic. However, half

of the participants interviewed reported that their HIV related symptoms such as generalised body weakness, fatigue and bodily pain were factors affecting their ability to do routine daily activities such as doing laundry or walking a long distance without being tired and that this negatively affected their QoL. This is consistent with previous qualitative studies (Ho et al 2010, Ming et al 2012). Those participants who reported declining physical functional independence or cognitive decline such as memory loss reported that this affected their QoL negatively.

The study also found that female participants were more worried about the changes in their body figure or image such as having body wasting and body rashes and spots. This gender difference has also been reported by Power et al (2013) in a qualitative study conducted in the UK. These findings from both studies also confirm and reinforce the need to prioritise gender-specific intervention for PLWHA.

Some participants also reported their sexual functioning had declined due to lack of body strength and fatigue. Furthermore, the qualitative data also highlighted other reasons for a decline in intimate sexual functioning among the participants such as the thought that they had contracted HIV through sex and therefore were fearful of infecting their sexual partners.

Impact of HIV on psychological well-being

Consistently both the quantitative and qualitative results of this study found that participants who were emotionally distressed due to their HIV status showed poorer QoL compared with those who were less emotionally distressed. This finding is consistent with previous studies that assess QoL in PLWHA in Southern Nigeria (Okunoye et al 2014, Okoror et al 2013, Olisah et al 2011), Uganda (Ezeamama et al 2016) and China (Ming et al 2013). In this study, the qualitative results found that the main causes of emotional distress reported by participants were: social stigma associated with HIV infection; the presence of HIV related symptoms such as body rashes and weight loss; inability to function like before their diagnosis. All these affected their general well-being and QoL negatively. Furthermore, the qualitative data also highlighted that thinking about being HIV positive reported by some participants was a cause of emotional distress because of the negative perception of society about HIV.

However, some participants interviewed said that they were not psychologically affected by their HIV status because of the immense social support they received from family and friends. Such support appeared to act as a buffer for participants to counter emotional distress.

More so, two participants reported that they sometimes experienced memory loss and had difficulty in paying attention to events around them and that this affected their well-being negatively. This finding is also noted by a cross-sectional study conducted in Puerto Rico that aimed to assess the impact of HIV related symptoms on QoL of PLWHA (Rivero-Mendez et al 2009). The poor cognitive function noted by the participants in this current study may be attributed to the cerebral manifestation of the HIV-associated neurocognitive disorder.

Impact of HIV on intimate relationships

The quantitative study found the participants with fewer symptoms significantly had better intimate relationships. Also, married participants had significantly better intimate relationships. This is similar to the findings by Bello & Bello (2013). Bello & Bello (2013) conducted a cross-sectional study to assess HRQoL among PLWHA in North-central Nigeria and found that unmarried participants reported lower (poorer) intimate relationships and lower overall QoL compared with married counterparts. However, findings from the qualitative interviews of the current study showed that poorer intimate relationships among unmarried PLWHA was related mainly to PLWHA being afraid of infecting others or self-withdrawal from sexual relationships. In general, it seems those who are unmarried may need targeting for support when considering effective interventions to improve HRQoL among PLWHA in Nigeria.

A number of the participants interviewed reported that their intimate sexual relationships had been affected negatively by HIV. Six participants reported a reduction in their sexual desire often due to perceived body changes linked to HIV and long-term effects of ART and a lack of physical strength. Three female participants chose to remain single due to a fear that potential partners would judge them poorly as a result of their diagnosis. Having HIV thus reduced the opportunities and/or desire for sexual relationships, which had a negative impact on their QoL. There were also concerns about infecting sex partners even though they were educated by healthcare providers on how to practice safe sex. All the participants acknowledged

heterosexual activity as a possible source of HIV infection and the moral imperative of disclosure to avoid “harming another”. However, this was difficult to practice as they perceived that their sexual partners might judge them negatively and some had had negative reactions from partners and did not want to risk it again. Psaros et al (2012) in their qualitative study also reported similar findings in a study that aimed to explore the intimate and sexual decision making among HIV positive women over 50. Psaros and colleagues found that stigma, changes in body image and the disclosure dilemma were the common causes of the poor intimate sexual relationships among their participants.

Importance of support from family and friends

As narrated by the participants, the quality of relationships with friends and family was acknowledged as being vital to their QoL and well-being. Both quantitative and qualitative results showed that better social relationships was associated with better overall QoL. This finding is consistent with several studies who also found that a supportive family environment significantly contributes to coping with chronic disease such as HIV infection both emotionally (that is, in terms of feeling loved) and instrumentally (that is, in terms of having someone to help care for their health needs) (Kumar et al 2015, Folarise et al 2012, Makoe et al 2008).

Furthermore, the qualitative data found from the narratives of two participants gave an insight into the importance of social relationships and the impact of HIV upon them. Despite having disclosed their HIV diagnosis to family and friends, these two participants said that they maintained a good social relationship with their family and friends and this gave them the strength to live with the disease. Four participants interviewed remarked that their social relationship with their family and friends had worsened as a result of the HIV status and that impacted negatively upon their QoL. The reason for the deterioration in social relationships was because the family member perceived the HIV status of the participants would bring or have brought shame to the family. Three female participants interviewed reported that HIV had caused divorce which was said to have affected their QoL negatively.

In line with previous qualitative studies in China (Ming 2012) and in South-western Nigeria (Adedimeji et al 2010), in this present study participants reported that their social relationships

had been adversely affected since being diagnosed with HIV. Domestic violence was reported to be a major cause of social disharmony reported by female participants and HIV infection was also reported as a major cause of divorce. This is consistent with the findings of a study conducted in Cambodia (Geurtsen 2005).

Supportive relationships with family and friends are likely to have a particularly high impact on the QoL of PLWHA in Nigeria due to a lack of state-provided social care services in the country. The only social support PLWHA receive in Nigeria is from family, friends or from their local associations which are themselves underfunded. Examples of such associations are networks of PLWHA in Nigeria, civil society for HIV/AIDS in Nigeria, the association of women living with HIV/AIDS in Nigeria and association of positive youths living with HIV/AIDS in Nigeria.

This study found older participants stressed that family support, especially from grown-up children, played a critical role in maintaining a better QoL. In Nigeria, it is part of the culture that grown-up children look after aged parents in both health and disease. The social support received from their family included empathy, financial assistance, advice on how to live with the disease by encouraging them to regularly take their ARVs or integrate them so that they can have more sense of belonging. In the Pacific Islands, a qualitative inquiry reported a similar finding that family support played a critical role in helping PLWHA cope with their disease and children in this setting where a similar source of strength and support to their parents (Pacific Island AIDS Foundation 2009).

A surprising finding from the quantitative data was that lower social support was significantly associated with better overall QoL. This is inconsistent with previous secondary data analysis to assess QoL among PLWHA in the US that used the same ISEL measure (Henderson et al 2012). It is also inconsistent with the qualitative results that revealed that participants that reported having much social support from family and friends reported having better QoL. The qualitative results showed that support from family and friends provided acceptance and encouraged them to adhere to the ARVs and also provided financial assistance. These conflicting findings between quantitative and qualitative results may be a result of the content

of some of the questions on the ISEL which were not appropriate to the North Eastern Nigeria context. As such, some of the items of ISEL-16SF used in the quantitative study might have resulted in possible response bias. For example, this question “if I had to mail an important letter to the post office by 5.00pm and couldn’t make it, there is someone who could do it for me”. In Nigeria, postal patronage is very low because of a lack of efficient postal services. Therefore, such a question might be confusing to some participants as they do not use such services. Another possible reason for the discrepancy is perhaps those people with more support were needier and had more symptoms. They may have received more support for example, with practical tasks such as doing laundry, house cleaning and shopping as they had greater need.

The findings of this study showed that living with chronic illness such as HIV had a significantly negative effect on quality of social interaction. The perceived social stigma associated with diagnosis and body image resulted in some participants restricting social activities outside their homes. Arguably, loss of friends and family may lead to psychological distress in PLWHA (Clingerman et al 2004). However, good social support can ameliorate some of the negative impacts of HIV on QoL and encourage health promotion behaviour (for example, adherence to ART).

Impact of financial difficulties on QoL

The quantitative results found that participants with less financial difficulties had significantly better overall QoL. This finding is similar with the one found in the previous study in the US (Vidrine et al 2005) who found PLWHA of upper socioeconomic status had significantly better physical and psychological functioning and overall QoL compared with those with lower socioeconomic status. The current study did not measure monetary income, but nearly 60% of the participants reported that they had never or rarely faced any financial difficulties in the last two weeks.

The qualitative results found that sex, marital status and age played a significant role in determining the impact of HIV on the income of the participants. For instance, married female participants acknowledged that their HIV status did not affect their income, as they got financial support from either their spouses or children. This is because most of them were

housewives and it is the cultural practice in Northern Nigeria for husbands to provide for their wives. Furthermore, older participants remarked that they did not have any financial difficulties as their children provided for them. It seems the single PLWHA and those with dependent children in North-eastern Nigeria are likely to be most vulnerable to financial difficulties.

The reason why all the participants stressed the importance of having a steady income may be because in Nigeria there is no 'state benefit or welfare system' as found in high-income countries to support people with financial difficulties.

High levels of stigmatisation

The quantitative data used two questions to assess stigmatisation: "I have been afraid of disclosing that I am HIV positive" and "I have been afraid of infecting others". The quantitative results found that participants with less stigmatisation had significantly better functional and cognitive functioning, intimate relationship and global PROQOL-HIV score. This result is consistent with previous studies in China (Liu et al 2013, Shan 2011).

The qualitative results further explained the nature of stigma, the sources of stigma and how the participants were able to manage it. Participants perceived that HIV related stigma was affecting their QoL. The qualitative data also added further insight by identifying three forms of stigma: actual stigma, internalised stigma and fear of being stigmatised.

Actual stigma was evident in stories participants told about being victimised by their family members (relations, spouse etc) or friends after being diagnosed with HIV. Participants remarked that the types of actual stigma were either in the form of gossip or avoidance to share cutleries or lavatory.

Internalised stigma, whereby people internalise the stigma held by broader society and devalue themselves was less evident. This finding could be a reflection of the strong family support that exists for most PWLHA in the present study. Perhaps, this helped them to cope and minimise the influence of self-stigma. The internalised stigma exhibited by some participants include the feeling of guilt about their HIV status and social isolation.

Fear of being stigmatised was evident in participants' stories about avoiding disclosure of HIV status to others. The experience of and/or fear of encountering stigma resulted in a number of strategies to minimise stigma. Some participants especially females avoided wearing short dresses while others were open about their HIV status and disclosed to others that they were living with the disease. The reason why some participants acted so differently by downplaying their identity may be because of their personality and for those that were open about the HIV diagnosis may be because they have more social support and knowledge about the disease. Some participants decided to keep their HIV status undisclosed to avoid being stigmatised and there is a strong possibility that this affected their QoL negatively. The qualitative data showed that the impact of stigma and stigma management on QoL is complex. Disclosure puts people at risk of being stigmatised, but non-disclosure means that they cut off potential support. This conundrum has also been highlighted in other studies (Chambers et al 2015, Mutabazi-Mwesigire et al 2014, Nyblade et al 2009, Geurtsen et al 2005).

Furthermore, the quantitative results found participants that were highly stigmatised had significantly poorer intimate relationships. This is also supported by the qualitative results, as some of the single participants interviewed especially females reported that they avoided getting married because they were scared of disclosing that they were infected by HIV or afraid of what a partner would say if their status was known. This mode of managing stigma was commonly reported by the female participants. In Uganda, Mutabazi-Mwesigire et al (2014) also reported similar findings in their recent study exploring QoL among PLWHA.

Participants who had disclosed to very few if any people stressed living in constant fear of disclosure of their HIV status as it would bring shame to them and their families and associate them with the label of promiscuity. As a result of this fear of disclosure, some participants isolated themselves or did not disclose to friends and family. This finding is consistent with many studies such as that conducted in India by Kumar et al (2015). Kumar and colleagues noted that women were most open about their feelings of shame associated with their HIV status and therefore, remained reluctant to disclose their HIV status to even family and friends.

Other researchers have reported that the threat of stigmatisation and lack of support are common reasons for non-disclosure of HIV infection (Hult et al 2012, Rodkjaer et al 2011).

The stigma associated with HIV infection is reflective of the society at large as it is influenced by social and cultural values (Chambers et al 2015, Nyblade et al 2009). In North-eastern Nigeria, HIV is highly stigmatised. It is still seen as a disease of shame and promiscuity, and it is associated with derogatory terminology. For example, common names for HIV by the some local are “*ciwon zamani*” [modern-day disease], “*ciwon diga*” [close to graveyard] and “7 plus 1¹”. Therefore, it is not surprising that participants reported either experiencing stigma and/or feared of being stigmatised by family and friends. Other studies have reported that PLWHA found disclosure to be extremely challenging as many feared “being judged” and “being rejected” (Kumar et al 2015, Okoror et al 2013, Ssali et al 2010). In the current study, in expectation of fear of being rejected some participants had desisted from disclosing their status even to their spouses or sexual partners. This isolation induced by stigma is very problematic, mainly when it leads to poor engagement in care and medication adherence (Kingori et al 2012, Mugavero et al 2009).

Regarding stigma management, one participant reported that taking ART regularly was the best way of managing stigma because the ART helped to mask the HIV related symptoms. This finding corroborates the findings of a recent qualitative study from South-western Nigeria which aimed to explore the impact of HIV stigma on ART adherence and found that the fear of anticipated and enacted stigma acted as a catalyst for PLWHA to strictly adhere to their ART medication (Okoror et al 2013). This was because looking ill was seen as a sign of being infected with HIV. Therefore, adhering to ART regimens among PLWHA helped them to look and feel healthy, eliminating or reducing even eliminating enacted stigma (Nyblade et al 2009, Sabin et al 2008).

However, paradoxically, in other settings stigma has been reported to be a key barrier to engagement with successful ART programmes (Chambers et al 2015, Herrmann et al 2013,

¹ “7 plus 1” is used to downplay saying AIDS straight away so that the PLWHA should not understand. Sum of 7 and 1 is eight and the pronunciations is close to AIDS without the ‘s’ sound.

Chen et al 2011, Seely & Russell 2010). Recently, Chambers et al (2015) in their systematic review noted that intersectional stigma was one of the key barriers to access to ART. Intersectional stigma (also called intensified-, multiple-, or double- stigma) is a situation where HIV-related stigma is expressed in relation to other types of marginalisation due to age, sexual orientation, gender identity, socioeconomic status, or ethnicity/race (Madru 2003). Institutional policy segregation of HIV care clinic from other speciality clinics within the health facilities and negative behaviour such as being ignored or infantilised, drawing disparaging comments, receiving neglectful care or being denied care due to a perceived denigrated lifestyle toward PLWHA by healthcare providers were among forms of the intersectional stigma that hinder access to care and ART among PLWHA. Thus, avoiding HIV care and access to ART in order to manage or avoid stigma, can be perceived as having a potential immediate benefit to one's mental well-being such as reduced stress stemming from anticipated stigma; however, afterward it could contribute to detrimental health outcomes and QoL in the long term (Herek et al 2005). At UMTM Maiduguri (the study setting) the HIV clinic is separated from other specialities within the hospital. However, the participants of this study did not report that intersectional stigma was a barrier to access HIV care and ART. This may be because, despite the association between HIV and promiscuity, PLWHA in Nigeria do not predominantly come from groups that were already stigmatised (such as men who have sex with men or injecting drug users).

Coping strategies of living with HIV infection

High levels of spirituality

In this study, the qualitative results showed that the participants adopted a number of coping mechanisms, these include spiritual beliefs, exercise participation and healthy eating among others. However, the quantitative study found only spiritual beliefs as a coping strategy. These differences were probably because of the close-ended nature of the questionnaire (PROQOL-HIV) used in the quantitative study while the open-ended nature of the qualitative interview allowed the participants to give more in-depth information about their lived experience living with HIV. For instance, the quantitative data used a single question to assess the impact of spiritual beliefs upon the QoL of the participants: "my spiritual or religious beliefs have helped

to live with HIV". Both quantitative and qualitative results found that participants with higher spiritual beliefs had a significantly better QoL. This finding corroborates with previous qualitative studies in Saudi Arabia that aimed to explore the lived experience of PLWHA (Omer et al 2014) and a recent systematic review of both qualitative and quantitative studies (Lee et al 2014), which also found that higher spiritual beliefs was associated with better overall QoL. This positive effect was more pronounced than negative religious coping– for example, feeling that one's illness is a punishment from God (Lee et al 2014, Szaflarski 2013, Chaudoir et al 2012). Further, the positive impact of spirituality on QoL stressed by the participants of this study may be attributed to the positive impact of spirituality on psychological well-being. It has been argued that greater involvement in spiritual activities was associated with lower stigma (Szaflarki 2013), lower emotional distress (Szaflarki 2013, Sowell 2000) and better psychological well-being in HIV (Maman et al 2009, Simoni et al 2000).

The majority (9 of the 14) of the participants interviewed described spiritual or religious resources as beneficial for coping with HIV infection. Participants stressed that initially when they were diagnosed with HIV, they saw their HIV diagnosis as a death sentence but they said that their belief in God had made them move on with life. Participants interviewed also emphasised the importance of prayers/supplications which they reported had significantly improved their QoL. Participants stressed that a greater level of spirituality was associated with less psychological distress and better QoL. Several studies have found that PLWHA repeatedly uses religious coping to find a sense of purpose/meaning in life, to cope with issues of shame, guilt and to deal with sadness and grief (Okunoye et al 2014, Hussien et al 2014).

In this study, Islam and Christianity were the two main religions practised by the participants. Ten of the fourteen participants interviewed were Muslims. Accordingly, the discussion in the section will focus mainly on the Islamic perspective. However, an effort is made to draw similarities and differences between the two religious beliefs. In North-eastern Nigeria, Muslims make up of over 70% of the population. Irrespective of religious beliefs, 90% of the entire population practice their religion and also place it as an important tool in their lives. Both Islam and Christianity believe in the presence of good spiritual forces that battle against evil

spiritual forces (Gruden 1994). Gruden (1994) reiterated that both religious practices preach that spirituality is led by God who is believed to be a Spirit Being who created the heaven and earth and is everlasting, omnipresent and omnipotent. As such, both Islam (Errihani et al 2008) and Christianity (Oyedepo 2005) encourage the sick to seek any current medical treatment available to bring about a cure or recovery, but at the same time seek spiritual help through supplication, remembrance of God and acts of worship to seek support and help from God during suffering and illness. Thus, it is not surprising that participants in this study considered spirituality as an important coping strategy to deal with their HIV status.

The spiritual beliefs about health and illness amongst many Muslims in Nigeria is the same as found in other Muslims dominated societies. It is believed that both the state of good health and illness are acts of God and are seen as a marvellous blessing. From an Islamic perspective, the sick are always taught to remain grateful to God, see it as part of life, and as a trial, however, not to oppose destiny and endure patiently, then there will be many rewards and recompenses for them (Musa & Pevalin 2016). Further, their sufferings will be rewarded with spiritual honours and gifts of forgiveness. For many Muslims, this spiritual belief and practice provide comfort in coping with their illness (Narayanasamy & Andrews 2000). This is because of the general belief among Muslims that God (Allah) is Supreme.

Somewhat similarly, Christians believe in the Supreme Being (Jehovah or God) that sent His Son Jesus Christ to die for the sins of mankind, and Jesus Christ rose from the dead to save man from hell, sickness and sin (Olukoya 2005, Oyedepo 2005). In Nigeria, this belief is incorporated in all walks of life by Christians in both Pentecostal and mainstream Churches (Anglican, Baptist and Catholic). Perhaps, the thought that God is in control among the Christians that participated in this study helped them cope with living with infection (Otur 2011). Specifically, today in Nigeria Pentecostal Churches have turned into prayer temples in which followers regularly ask for prayers from the Pastors (Prayer Warriors) to seek deliverance and divine healing (Otur 2011).

Other coping strategies: Exercise, nutrition and ARV adherence

The quantitative results pointed only to religion as a coping strategy used by the participants however, the qualitative results found that some participants used a number of coping strategies including healthy eating, regular physical exercise (regular going to gym for exercise and playing football) and adhering to ART which they said had helped to improve their well-being and QoL. This highlights the relatively rigid nature of quantitative approach compared to the flexible nature of the qualitative inquiry. This current study found that younger participants were those that used exercise as coping strategy. Oyeyemi et al (2013) confirm this in their cross-sectional study aimed to examine the prevalence and correlates of physical activity among adults aged between 20 and 80 years old in Maiduguri North-eastern Nigeria. Oyeyemi and colleagues found that physical activity participation significantly decreased with increasing age after controlling for potential confounders. As reported by Clingerman et al (2004), this study found regular participation in leisure physical activity improved QoL of PLWHA. Another reason why physical activity participation was used as a coping strategy by some participants may also be related to its effects on psychological well-being (Gomes Neto et al 2015).

In this study, some participants reported that managing to integrate HIV and ART into their daily routine was a means of inspiration to cope well, and better their QoL. This was related to the benefit they derived from adhering to the ART. Participants stressed that taking ART regularly enabled them to live without opportunistic infection and even gain body weight making them look like someone living without HIV (see the impact of HIV treatment on QoL below for more details). These findings are in line with previous studies in Uganda (Atuyambe et al 2008, Wagner et al 2011) and Malawi (Kaler et al 2016).

Some participants (5 of the 14) stressed that healthy eating was used as a coping strategy. This finding is in agreement with the results of Thapa et al (2015) who conducted a cross-sectional study aimed to examine the prevalence and correlates of under-nutrition among PLWHA in rural Nepal. Thapa et al (2015) found that under-nutrition was associated with low body mass index ($<18.5\text{kg}/\text{m}^2$), poorer coping with HIV and QoL. This may suggest that poor nutritional

status in PLWHA speeds the disease progression, increasing the risk of morbidity (including opportunistic disease), reducing survival time (Palermo et al 2013, Tiriyayi et al 2012) and being associated with poor adherence to ART (Anema et al 2009, Hsu et al 2009).

Impact of ART on QoL

Better treatment impact was associated with higher functional status, better perceived general health and overall QoL. These findings are consistent with the results found in previous studies in high-income countries such as France (Côté et al 2009), Spain (Carballo et al 2004), middle-income countries such as Brazil (de Silva et al 2014) and low income countries such as Malawi (Kaler et al 2016) and Uganda (Atuyambe et al 2008).

Findings from the qualitative results also showed that participants remarked that adhering to their ART had helped in preventing them from having HIV related opportunistic infection. According to some participants' poor adherence to ART increases the risk of having their CD4+ count deteriorate and also increases the risk of their health deteriorating. Furthermore, some participants acknowledged that since the commencement of the ARVs they noticed a significant improvement in their general health and overall QoL when compared to before they started taking the ARV. The qualitative results also found that participants were very optimistic about the ART and that they see it as a lifeline. They contrasted this to before the initiation of the ARVs when some of the participants said they felt hopeless and worried about their health and death.

After the commencement of ART, their health became better, and they reported less worries about their health due to the significant improvement in their well-being and being able to do their daily activities easily without being tired easily like before. However, the way that the participants described 'playing with ART' suggested that the relationship they had with ART treatment and QoL was complex and that only after 'playing' with the dose and frequency of ART medication had they accepted that it resulted in improved health and improved QoL.

This complexity may explain the discrepancy in results regarding ART and symptoms. The quantitative results found that treatment impact had no significant impact on symptoms score. This is contrary to the findings of the qualitative results as the participants reported that regular taking of ARVs had led to a reduction in HIV related symptoms such as persistent fever, cough, skin rashes and weight loss. The difference may also be attributed to the fact that all the participants were already initiated on ART and most of them were doing well on ART and reported a relatively low level of symptoms or that they were asymptomatic and thus any association between treatment and symptoms may not have reached statistically significant levels. Another possibility for the discrepancy may be the difference in time between the quantitative and qualitative assessments. In the PROQOL-HIV questionnaire, participants were asked to recall symptoms in the previous two weeks while the narratives of the participants in the qualitative study related to the time since HIV diagnosis. Thus, in the qualitative interviews, the participants were drawing upon a much longer period in which they may have experienced symptoms.

The qualitative inquiry has shown that availability and adherence to ART has had a remarkable impact on QoL. ART has been reported in several literatures to have a positive effect on changing the view of HIV/ AIDS from a deadly disease to a potentially manageable disease, increase life expectancy of PLWHA and consequently leading to improved survival and reduction in opportunistic infections (Herrmann et al 2013, Mbada et al 2013, Dibb & Kamalesh 2012, Adedimeji et al 2010). The provision of free ART began in 2003 in North-eastern Nigeria and the University of Maiduguri Teaching Hospital, and since then there has been a constant supply because the programme is funded by the Federal Government of Nigeria and international donor agencies such as UNDP, GAIN, PEPFAR, and USAID under the supervision of NACA. Before the availability of free effective ART services in North-eastern Nigeria, HIV was among the highest cause of death among young people especially truck drivers and female food vendors, but since the start of this programme, this has significantly reduced.

Participants acknowledged that the provision of free ART in Nigeria more than a decade ago, resulted in a positive change in their livelihood and well-being. However, participants spoke about “playing with ART” referring to not adhering correctly to the medication regime. Their behaviour changed when this negatively affected their health. Participants were thereafter generally eager to strictly adhere to their routine medication. This positive attitude towards adherence was related to counselling provided by the healthcare providers while initiating the ART, bad experiences of deteriorating health as a result of ‘playing with ART’, fear of death and fear that their health will deteriorate. These findings support those reported in several studies in Uganda (Mutabazi-Mwesigire et al 2014, Atuyambe et al 2008, Russell & Seeley 2010) and South Africa (Robin 2005). These studies consistently report that significant disruption of life, experiencing coming close to death, loss of family members and loss of hope for the future were key issues that led the participants to adhere to ART.

Because of the availability of free ART in Nigeria, most of the participants initiated ART immediately after diagnosis as they met the WHO criteria for ART initiation. These participants reported good health since initiating ART and continuing to live their lives as before diagnosis. Provision of free ART to the participants has helped the participants live a longer life (NACA 2011, FMOH 2011), provide for their family (especially the male participants) and fulfil their life goals.

However, some of the participants in this study showed a poor attitude toward ART adherence. For these participants, the size of the pill and side effects were the major causes of poor adherence to ART. This is somewhat different to the findings of Adedimeji et al (2010) in a study conducted in South-western Nigeria. Adedimeji and colleagues found the cost of transportation and cost of enrolling on ART (for example, the laboratory test for CD4+ count, tuberculosis screening and drug) and irregular availability of the ARVs at the government designated HIV care centres as the causes of non-adherence to treatment. All the participants in the current study had access to ART as the sample was recruited from an HIV clinic which treated PLWHA with ART. However, the political insecurity in the region did have an impact on PLWHA’s access to ART. Those who stayed in the villages may not have been able to

reach the hospital on a regular basis, and their treatment may have been interrupted due to the political conflict in the area. It is also likely that the study sample did not include them as they were probably not regularly attending the clinic during the conflict. However, due to the political conflict, many people in towns and villages of Borno State moved to Maiduguri for safety. For these people, displacement and coming to Maiduguri will have improved their access to treatment.

Impact of insecurity on HIV care, health and QoL

This study has provided unique insight into the impact of political conflict linked to Boko Haram insurgency upon QoL and access to HIV care. Most participants reported that the political unrest had affected their QoL negatively. This finding is consistent with a previous prospective longitudinal study that examined the association between HIV infection and stressful events on HRQoL among 922 (705 HIV+ and 217 HIV-) Rwandan female genocide survivors (Gard et al 2013). After controlling for CD4+ count, age and symptoms of depression, Gard et al (2013) found that women with high post-traumatic stress symptoms significantly have lower overall QOL than women with fewer post-traumatic stress symptoms.

The reason why participants in this current study reported having reduced QoL may be attributed to the psychological trauma they faced due to the destruction of lives and properties. These may include some family members and friends being killed, and their houses were also destroyed. For example, seven of the participants were internally displaced persons (IDPs) which itself may have a negative impact on their psychological well-being. Two of the participants remarked that the political conflict in the study setting had a more devastating impact on their QoL than the HIV due to the massive loss of lives and properties. Mills et al (2006) put it that political unrest causes massive destruction of major infrastructure and utilities, resulting in a lack of shelter and energy sources, deterioration of safe water supply and sanitation services, lack of access to healthcare services, food insecurity and overcrowding.

Participants also reported that the political conflict in the study setting had sometimes limited their access to HIV care. This was mainly due to lack of access to roads whenever there was an attack by the insurgents. This finding is similar to that of Olupot-Olupot et al (2008) who

conducted a qualitative study that explored the impact of conflict on adherence to ART among 40 PLWHA living IDPs camps in North-eastern Uganda using focus groups. They found that fear of abduction and killing, cost of transportation from the IDPs camp to the health facilities to access care and hunger were barriers to access and adherence to ART. They also found that lack of regular workforce (health care providers) at the health facility was stressed by their participants as a barrier to access ART because most of the healthcare providers reside in towns far away.

However, the participants of this current study who were IDPs did not report living in IDPs camps, as all of them indicated they were living with relations in Maiduguri. Therefore, social support from relatives in the form of provision of shelter and financial support to pay for transportation to the hospital may have been crucial to the participants in the present study. Further, the reason why the participants in this current study did not point out the lack of human resources as a barrier to ART access may be because of availability of considerably skilled clinical staff (doctors and nurses), all of whom reside inside the hospital environment or outside staff (doctors and nurses), all of whom reside inside the hospital environment or outside of accommodation within the Maiduguri metropolis and were, therefore, able to get to their work at the hospital.

Reflections on using the revised Wilson and Cleary model to assess QoL of PLWHA on ART in North Eastern Nigeria

This study found that the data from North-eastern Nigeria adequately fit the model, signifying that disease status, functional status, personal characteristics and environmental factors are critical concepts in determining overall QoL of PLWHA in North-eastern Nigeria. This finding is consistent with the findings reported by studies conducted in the US (Henderson et al 2012, Sousa & Kwok 2006, Vidrine et al 2005).

Also, this study found the variances that explained each of the five endogenous latent variables (symptoms status, functional status, general health perception and overall QoL) were more than 80%, except for biological functions which is 5%. It could be that biological function as an integral part of the disease process for HIV is not as important to PWLHA in North-eastern

Nigeria compared to other external variables. As depicted by the model the variance that explained biological functions is accounted by variance in the exogenous latent variables (characteristics of the individual and environment). Therefore, the weak explanatory impact of biological functions is related to a relatively weak link found between biological functions and characteristics of both the environment and the individual. However, this finding is contrary to the findings of others that found nearly 20% of variance which explained biological function (Henderson et al 2012, Sousa & Kwok 2006, Vidrine et al 2005). The reasons for these differences may be attributed to the non-examination of the whole Wilson and Cleary model by the previous studies. Compared to the present study, Sousa & Kwok (2006) and Vidrine et al (2005) did not include characteristics of the individual and environment in their analysis. Another reason for the difference is that specific latent variables in these studies (Henderson et al 2012, Sousa & Kwok 2006, Vidrine et al 2005) were measured by a single variable. For example, Vidrine et al used CD+ count and pain intensity as the only measure of biological function and symptom status respectively. Sousa & Kwok used CD4+ count as a single measure of biological function; and Henderson et al used only MOS-HIV physical health summary and satisfaction with life scale as a measure of functional status and overall QoL respectively. Blunch (2013) and Pedhazur (1997) suggest that as a rule of thumb you need two or more measured variables per latent variable to conduct a reasonable SEM.

It could be that biological function as an integral part of the disease process for HIV is not as crucial to PWLHA in North-eastern Nigeria compared to other external variables. As depicted by the model the variance that explained biological functions is accounted by variance in the exogenous latent variables (characteristics of the individual and environment). Therefore, the weak explanatory impact of biological functions is related to a relatively weak link found between biological functions and characteristics of both the environment and the individual.

The revised Wilson and Cleary conceptual model provided a useful framework for this study and had helped in assessing the multidimensional constructs of HRQoL and also provided a better understanding of the relationships between them including a list of variables that impacted on QoL of PLWHA in North-eastern Nigeria. The model has helped in evaluating

how or if QoL domains were associated to one another and, due to the cross-sectional nature of the study design, to tentatively interpret the meaning or the pattern of the relationships. The use of the revised Wilson and Cleary conceptual model has helped in identifying that QoL domains that were mediated or moderated by the disease (that is, biological functions, symptoms etc), access and adherence to ART and characteristics of the individual and environment.

However, the model also has a number of shortcomings. First and foremost, is its breadth and comprehensiveness. While this has advantages regarding providing a conceptual framework for understanding and studying HRQoL, it also has the disadvantage of being a very blunt tool regarding its application. It covers many QoL domains and enables flexibility concerning how these may be measured. There is a lack rigour in the guidelines for the measurement of variables. Therefore, each researcher can decide how best to measure each element of the model. As a conceptual model, it provides a broad framework to assess HRQoL in a given population and is, therefore, able to 'fit' almost any setting. The flip side of this universal application is that it offers little insight regarding discriminating between different settings.

Key findings and implications of the study

The key findings of this study suggest that HIV could impact multiple dimensions of QoL of PLWHA. Specifically, HIV can negatively impact social relationships with family and friends, intimate relationships, physical functioning, mental well-being and cognitive functioning, and finance and work of PLWHA in North-eastern Nigeria. These findings uniquely identified the critical domains of QoL that could be targeted when designing interventions to improve QoL of PLWHA in the understudied region of North-eastern Nigeria. The results provide an addition to the literature by documenting from an understudied population that beyond the physical dimension of health, other important social and cognitive aspects of well-being could be negatively impacted by the HIV process among PLWHA. The findings also indicate strikingly high levels of stigmatisation among PLWHAs as well as high levels of spirituality which is used by many as a coping strategy to deal with their condition. This study was conducted in a resource-constrained setting where there was a lack of state social support and where there was political unrest. The evidence from this study is unique and relevant to informing efficient

healthcare delivery and support for PLWHA in the North-eastern region of Nigeria and other areas with political conflicts and lack of state support.

The relevance of this study was to add to the body of knowledge regarding the health-related quality of life in people living with HIV/AIDS, as infected persons are living longer and numerous factors affect their health-related quality of life. The quantitative findings provide a further understanding of the process through which objective health determinants contribute to general health-related and HIV-specific QoL as assessed by the PROQOL-HIV questionnaire. The findings have shown that ART intake was associated with better health (as measured by CD4+ count but can also have a negative impact on QoL due to side effects). Further, the path analysis showed that the direction of impact proposed by the Wilson and Cleary model seemed to apply to PLWHA in Nigeria.

In this study, the large sample size and SEM have provided a tentative validation of the revised Wilson and Cleary HRQoL model for PLWHA living in a conflict area of North-eastern Nigeria. The model has contributed to better understanding of the determinants of QoL by providing a framework that explains its determinants (Wilson & Cleary 1995). This comprehensive model includes a full range of variables typically included in health-related quality of life assessments from two different paradigms (biomedical and social science). The revised Wilson and Cleary suggests that health-related measures fall along a continuum, beginning with biological function and ending in overall HRQoL. With the better understanding of the phenomenon of health-related quality of life, interventions to improve patients' perceived health-related quality of life can be targeted to the underlying causes (Ferrans et al 2005, Wilson & Cleary 1995). Although the model has been validated in other population such as type-2 diabetes (Chia 2007), chronic kidney disease (Kring 2008) and coronary heart disease (Ulvik 2008) until now, there had been no empirical studies of this model with a sample of people with HIV.

While the Wilson and Cleary conceptual model provided a useful framework for this study to look at the various domains impacting on QoL, as noted above, it is perhaps too blunt instrument to detect local variation. SEM used in the analysis is a reliable analytical instrument,

it has helped to examine the relationships between the various QoL domains simultaneously. Nevertheless, causation between the HRQoL components cannot be implied from the SEM because of the cross-sectional design of the study.

The qualitative study has provided a better understanding of the meaning of the associations which emerge from the quantitative study and it also provided a deeper understanding of the impact of HIV on QoL. Health-related quality of life is a complex phenomenon, and the qualitative study was able to address some aspects such as the impact of political conflict (insecurity) on QoL, health and access to HIV care which was not examined in the quantitative study. The additional insights provided by the qualitative study suggest that it is imperative for the clinicians and policy makers involved in HIV care in Nigeria to focus on evidence-based research that goes beyond the identification of determinants of health-related quality of life in PLWHA. Therefore, they should focus more on intervention targeting the determinants of QoL such as improving social and economic supports, reducing stigmatisation and psychological support for PLWHA.

Strengths and limitations of the study

Strengths of the study

A major strength of this study is the use of a mixed method to assess both objective and subjective HRQoL in PLWHA in a resource-constrained setting. The quantitative data provided measures about the impact of HIV on the QoL, and the qualitative data was able to provide insight into the relationships found between the QoL domains in the quantitative data as well as information about the lived experience of HIV. This facilitated not only a measurement of impact which had not previously been conducted in North-eastern Nigeria but also in-depth data to provide insight and contextual understanding.

The mixed method approach facilitated quantitative analysis of a large sample stratified by age group and gender. While it was a non-randomised stratified sample, regarding age and gender, the participants were representative of PLWHA receiving HIV care in North-eastern Nigeria.

The participants of the qualitative study were selected from those who took part in the quantitative survey, and they were stratified by age, gender and overall PROQOL-HIV score (that is, low, moderate and higher score). This ensured a collection of relatively heterogeneous narratives on how living with HIV affected QoL.

What is unique in this study is the impact of political conflict (insecurity) as this has not been examined in other studies. The presence of political conflict may contain valuable information related to quality of life.

Limitations of the study

The study design for the quantitative study was cross-sectional, and the research objectives were to examine the relationships between components of the revised Wilson and Cleary conceptual model. However, a cross-sectional study cannot measure the causal effects between two or more variables and this limits interpretation, causality and the generalisability of the findings of this study. A longitudinal cohort study would be needed with data collected from different time periods in order to assess the causal relationships. The reason for the choice of cross-sectional design in this study was the lack of time to conduct a longitudinal study for an educational degree. Despite the limitation of the cross-sectional design, the findings of this study will serve as a baseline or pilot for understanding the key determinants of QoL among PLWHA in North-eastern Nigeria. In addition, path analysis and SEM were used to go some way towards addressing this shortcoming. These analyses were systematically carried out as per the causal links depicted by the revised Wilson and Cleary model. SEM is a reliable data analytic tool that gives precision in testing theories and evaluating construct validity, but it cannot be used to imply causality. The prediction of the direction of relationship in SEM is not possible when used in a cross-sectional study however, it nevertheless generated a directional model.

Another limitation of this study was the inability to include the viral load of the participants as one of the measures of biological functions. This is the amount of HIV in the bloodstream. A higher viral load indicates that the patient has more HIV in the body, and signifies that the immune system is not fighting HIV well. A viral load test helps provide information on the

health status and how well the ART is controlling the virus. Lack of use of the viral load in this study was because not all participants have up to date information on viral load as the setting where the study was conducted stopped testing it due to logistical reasons. Thus, a future study should include viral load as a measure of biological function to assess HRQoL among PLWHA receiving ART. Nevertheless, CD4+ count was collected, and this is a relatively accurate indication of biological function.

Another limitation of the quantitative study is that a number of the determinants of overall QoL measured by global PROQOL-HIV score form part of this measure. Thus, it is to be expected that they will be significantly associated with overall QoL. For example, treatment, future, stigmatisation, and emotional distress were all measured with the same PROQOL-HIV. The consistency in findings of this current study with most of the previous studies (Henderson et al 2012, Nokes et al 2011, Phaladze et al 2005) may be because they all used a single HIV-specific QoL instrument to measure some of the latent variable (for instance, functional status, general health and overall QoL). Perhaps, the results might differ if independent measures were used to assess these latent variables. However, Durancinsky et al (2012b) used EQ-5 generic QoL and MOS-HIV HIV-specific instruments to assess the concurrent validity of the PROQOL-HIV instrument and found the PROQOL-HIV correlated significantly with these two instruments.

Additionally, one of the limitations of the quantitative study is the nature of how certain questions do not measure/assess what it meant to assess. For instance, one of the questions of PROQOL-HIV questionnaire that assess stigmatisation 'I have been afraid of infecting others', is not a direct measure of stigma but more about the genuine fear that they may infect other people. Therefore, this is one of the potential limitations of the PROQOL-HIV questionnaire and thus also is a limitation on the accuracy of the quantitative associations reported between stigma and QoL in this study.

While care was taken to ensure that the age and gender of the samples for the quantitative and qualitative studies reflected the composition of PLWHA attending the clinic, it was nevertheless a non-random stratified sample. This technique was chosen because of the large

sample size required for the quantitative study and the short period of the study. The use of a non-random stratified sample increased the risk of selection bias, and this limits the robustness and the generalisability of the findings. Probably participants who were good attendees and good at taking their medication and perhaps had a better QoL were more likely to have volunteered to take part in this study. Random sampling would have provided a more representative sample and therefore more robust results.

In the in-depth interviews, steps were taken to minimise bias, but it was still the case that some participants were reticent to express themselves as they felt that the researcher knew better and considered him as an expert. This was a clinical sample of PLWHA attending a hospital, and the interviews were conducted at the hospital. Also, the researcher had previously worked as a clinician at the hospital where participants were recruited although steps were taken to downplay the clinical aspects during the interviews.

Lack of inclusion of potential participants who could not understand at least Pidgin English in the in-depth interviews posed a risk of bias of true representation of people in the study setting. This implies that the views of the less educated non-English speakers were not represented in the qualitative results. Therefore, future research should include less educated non-English speakers to have more comprehensive representation.

Reflexivity and reflection of bias

A researcher's interests, culture, beliefs and values invariably impact on research. Therefore, reflexivity should be an important part of the research process. Danielewicz (2001 p.1555) argues "reflexivity as an act of self-conscious consideration that can lead to a deepened understanding of themselves and others, not in an abstract, but concerning specific social environments ...[and] foster a more profound awareness ... and how social contexts influence who people are and how they behave...".

As being the researcher, I have similar religious beliefs and shares the same cultural background with the participants in the study area; this could have affected his critical reflection of the actions and attitudes of the individuals. For example, HIV is a highly

stigmatised disease in the society where the study was conducted and this aspect was initially somewhat I have overlooked and assumed that HIV was highly stigmatised in all settings.

In other ways, I was perceived as an ‘outsider’, and therefore, I was cautious to avoid his influence in the research process. The factors that I was cautious about were communicating to my participants, as such my values, interests, experiences and scientific knowledge about HIV infection such as mode of transmission and its impact on health and well-being. Furthermore, I discussed with my supervisors about my knowledge about the study setting, potential participants and the system in place for providing care for PLWHA in North-eastern Nigeria; I became aware of the potential bias of my constructions of the meanings of the collected data/observations.

On reflection, engaging in reflexivity in greater depth during the initial stages of writing this thesis may have facilitated a different set of decisions. For example, it would have influenced my decision to exclude from the qualitative study those who do not speak English Language (both Pidgin and grammatical English) which I have reflected on above.

One of the goals of reflexivity is to gain understanding from experience to change future practice. Although this thesis turned out to be expansive; I have learnt the importance of an ongoing documented reflexivity in any qualitative research study I will be involved with. This includes the creation of a reflexive journal to provide a trail of decisions made and an awareness of my influence at every stage of the research. During the qualitative study, I kept a very basic reflexive journal, however, in retrospect the I have learnt the value of reflexivity throughout the research process, and in the future, I would keep a detailed reflexive journal.

In Chapter Three on pages 145 – 151 there was a discussion on the researcher’s position throughout the qualitative study. In some instances, I played a role as an insider while in some place I acted like an outsider. This blended insider-outsider position had benefits, challenges and implications for the research process.

Regarding benefits, my familiarity with the setting facilitated instant access to and rapport with research participants (Chavez 2008). The researcher’s insiderness helped to provide an insight

of understanding the linguistic, cognitive, emotional and psychological precepts of the research participants as well as the historical and practical day to day events in the study area (Chavez 2008). However, 'insider' positionality also posed challenges to the research process. The insider positionality could negatively affect the data collection process. Researchers in this position could have biases in interviewing (Zavella 1996) or may not seek in-depth understanding of the issues as they consider themselves as 'knowers' of the subjects being studied. In this way, awareness of insiderness challenges the investigator to be fully and continually cognisant of his researcher role (Kusow 2003).

More so, my social values such as cultural norms might constrain the questions I asks and how I asks them for fear that people might consider me as a 'socially immoral' person (Chavez 2008). Being influenced by internally held moral or social positions thereby has the potential to compromise the qualitative data collection process and thereby constrain the researcher's performance of the research role and objectives (Parameswaran 2001). Furthermore, if participants are aware of my values, they might respond in a way that they know will not offend my known or perceived identity (Merriam et al 2001).

The insider positionality could also lead to selective reporting or failure/difficulty to recognise patterns in the data during analysis due to familiarity with the community (Chavez 2008). The inability to note and analyse the 'taken for granted' might mean that I overlook some of the themes which might otherwise emerge from the data as vital influences of HIV infection on QoL among participants. For example, I took the level of stigma for granted and almost overlooked this aspect but the supervisors noted that it was very marked.

In general, the insider-outsider position posed methodological benefits and challenges particularly on matters around positionality in the research process. In this study, I negotiated my positionality, drawing on his own diverse social identities (Labaree, 2002) during interactions with participants to minimise biases in the research data and to conduct ethical research (Hopkins 2007).

Recommendations

Currently, HIV care in Nigeria is biologically driven through the provision of ART, and the prognosis is measured by biomarkers namely CD4+ count and viral loads. The information from this study could assist public health practice and healthcare providers to provide more targeted support and self-management strategies to PLWHAs and their families. Public health practice should engage in regular training of healthcare workers in HIV care so that they view the patient holistically rather than focusing exclusively on their biomarkers. Also, HIV healthcare providers should adopt holistic HIV treating strategies that encompass all aspects of life and well-being. This will impact positively on the QoL of PLWHA in Nigeria. As such, the following recommendations are made in respect to the key findings.

HIV and social relationship

Due to the high rates of stigma and the negative impact, this has on QoL, the HIV control programme in Nigeria should work towards building a better understanding of HIV and teaching positive attitudes towards PLWHA among families. This may lead to quicker acceptance of family members thereby enhancing their capacity to support their friends and family living with HIV effectively.

Work and finance

The importance of the ability to work and remain economically active was highlighted in this study. Therefore, the incorporation of skills development and employment assistance into HIV support programmes may strengthen the roles of PLWHA in positive coping.

This finding suggests that financial independence is important to good QoL among PLWHA in Nigeria, and has implication for the ability for PLWHA to provide the basic needs of life for themselves in a low resource setting like North-eastern Nigeria. In Nigeria, it seems that the National Workplace Policy on HIV and AIDS – 2013² (Federal Ministry of Labour and Productivity (FMoLP) 2013) needs to be strengthened and applied more efficiently to improve

² This is the Nigerian Government policy directed at eliminating barriers to job access including discrimination and stigmatisation from employers. The policy is mandatory for employers of labour in all sectors of the Nigerian economy including the private and public sectors and the formal and informal economies; as well as the armed forces and other uniformed services.

the financial status of PLWHA in Nigeria and indirectly their QoL. Among other objectives of the policy includes protection of the rights of PLWHA and ensuring confidentiality of their status is strictly adhered to according to the data protection act of Nigeria in all workplaces.

Stigmatisation

Public health programmes should work towards removing the aura of ‘shame’ and ‘guilt’ that surrounds HIV transmission, and this would be an important step towards reducing stigma, enhancing disclosure and reducing anxiety experienced by PLWHA in Nigeria.

Also, organisations and programmes that support and empower HIV-positive people the need to be recognised and continue to receive support. It is hoped that recognition and support of these programmes will ultimately reduce HIV transmission and allow people who live with HIV to live a life free of stigma and discrimination.

The findings from this study suggest the need to improve psychosocial support services for HIV-infected people in North-eastern Nigeria to help them manage the stigma of HIV. PLWHA support groups may also have a role to play in stigma management. This is consistent with evidence from Latin America, Africa and Asia where involving PLWHA in providing services for other PLWHA empowered them and gave them a sense of fulfilment (Pulerwitz et al 2010). Nyblade et al (2003) also noted that becoming part of a support group of persons with the same condition is one way of coping with stigma.

Coping strategies

The impact of spirituality as a coping strategy emerged in both the quantitative and the qualitative interviews. Thus, it is imperative for policymakers’ in the HIV prevention and control programme in Nigeria to integrate spiritual support strategies to help PLWHA cope with their illness. In Senegal, the integration of spiritual well-being in HIV care programmes has been found to be an important factor in challenging psychosocial problems and supporting coping (Ansari & Gaestel 2010). This will help to improve and guide social and individual beliefs on health and the care of persons with chronic diseases such as HIV.

The benefits of ART adherence, physical activity and good nutrition were also highlighted by participants as a means of coping with HIV. Therefore, public health should always re-emphasise benefits of good nutrition, physical activity (that is, mild to moderate activities such as walking, running, jogging, gardening etc for at least 30 to 60 minutes 3 to 5 days a week) (Oyeyemi et al 2013) and ART adherence to people infected with HIV soon after diagnosis.

Several studies have shown adherence to ART significantly reduced the risk of opportunistic disease, improve QoL, reduced risk of morbidity and death in HIV patients (Alomepe et al 2016, Mutabazi-Mwesigire et al 2014, Herrmann et al 2013). Therefore, these benefits of ART adherence should be well emphasised to PLWHA in North-eastern Nigeria when initiating ART.

Regular and healthy eating is said to help in reducing the risk of ART-related side effects such as dizziness, stomach ache etc (Palermo et al 2013, Hsu et al 2009). It is also argued that ART adherence with adjunct healthy and regular eating reduces the risk of disease progression and increased the survival rate in PLWHA (Tiriyayi et al 2012, Anema et al 2009).

Physical activity participation is a cost-effective health promotion intervention that could significantly alter the use of healthcare resources, decrease health care cost, slow disease progression and prevent the development of other comorbidities in chronic diseases (Vancampfort et al 2017) including PLWHA (Gomes Neto et al 2015, Hand et al 2009, Ciccolo et al 2004, Clingerman et al 2004). Due to the low level of resources in the study setting (Garbati et al 2011) paying for gym services to engage in regular exercise may not be obtainable. Also, the conservative nature of Northern Nigeria (Ghinai et al 2013) means that the out-door participation of physical activity among female Muslim PLWHA may be difficult to achieve. Therefore, attention needs to be given to encourage PLWHA to be participating in leisure physical activity such as gardening, jogging, cycling, brisk walking, dancing etc.

Insecurity

Acknowledging key barriers to access HIV care and adherence to ARVs is imperative to improve access to healthcare for this vulnerable group efficiently. The security concerns and

logistical constraints stressed by interviewees in this current study merit attention from public health practitioners and HIV care providers who need to liaise with relevant government security agencies to improve security. The study setting is facing a humanitarian crisis because of the political unrest, and many people are living in poverty as result of the destruction of fortunes (Aljazeera 2011). Therefore, public health practitioners and HIV health care providers should encourage the government at all levels in Nigeria and non-Governmental Organisation to provide food vouchers to PLWHA as it will go a long way to help increase adherence to ART and to adjust and cope with the HIV.

Conclusion

Since the introduction of effective ARV therapy, mortality and morbidity among PLWHA has considerably reduced which has changed the HIV/AIDS from being an acute fatal disease to a manageable long-term illness. Increased life expectancy for PLWHA makes QoL a key outcome measure for patients and providers of medical and social services. HIV infection is a disease that does have not only a biological impact but also impacts on the social, psychological and physical dimension of health and well-being. Understanding the major determinants of QoL has implications for the care of PLWHA because of its integration into assessments of quality of service delivery, health outcome and cost-effectiveness analysis in both research and clinical practice to inform decision making in improving HIV care. Nigeria is ranked second highest after South Africa for the prevalence of HIV in sub-Saharan Africa yet little is known about QoL of PLWHA in Nigeria, and this study is the first to be conducted about this in North-eastern Nigeria.

This study systematically examined the determinants of HRQoL of people infected with HIV in North-eastern Nigeria using a newly developed HIV-specific questionnaire (PROQOL-HIV) and in-depth interviews. This assessment was guided by the revised Wilson and Cleary HRQoL conceptual model. The findings suggest that the PROQOL-HIV questionnaire is appropriate to assess QoL of PLWHA in North-eastern Nigeria

Also, the validation of the revised Wilson and Cleary model showed that the model fit the data adequately and the relationships between all its domains were all statistically significant. This implies that the revised Wilson and Cleary conceptual model applies to PLWHA in North-eastern Nigeria and provides a useful framework to understand QoL in this context. The model was developed and subsequently applied to study QoL in high-income countries. Its applicability in North-eastern Nigeria suggests that it is a model that provides a useful framework to study QoL in very different settings. However, the revised Wilson and Cleary conceptual model is too blunt an instrument to assess the impact of political conflict on QoL of PLWHA in North-eastern which was explored by the qualitative study. A qualitative approach was necessary to show that political insecurity had a profound negative impact on access to adequate HIV care and QoL of the participants. The qualitative data was also needed to gain insight into the profound impact of stigma on PLWHA QoL.

This study has thus provided an extensive understanding of HRQoL among PLWHA in the conflict area of North-eastern Nigeria. This will serve as a foundation for the evaluation, identification and ways to promote pertinent, compassionate, and culturally sensitive pragmatic health care to PLWHA. Further, the study has provided a better understanding of what is socio-culturally important, satisfying, and valued to PLWHA in North-eastern Nigeria that will enable policymakers and healthcare providers in accepting, negotiating and reforming HIV/AIDS care services within the context of their patients/clients.

Although a cross-sectional survey does not measure causal relationship as proposed by revised Wilson and Cleary model in assessing QoL however, the findings of this study could be a preliminary/pilot study to assess QoL among PLWHA in any conflict areas around the world with similar demography and socioeconomic status. The narratives from the qualitative findings revealed that PLWHA receiving ART in North-eastern Nigeria perceived the political conflict in the region to have had a more profound negative impact on their health and QoL than the HIV infection itself despite the detrimental consequences the HIV had on their health, psychosocial well-being and QoL.

The results of this study denote the need to improve the security situation in the region and psychosocial support services for HIV-infected people. Thus, integration of spiritual support service will go a long way in helping PLWHA in Nigeria in coping with the disease as the majority of the participants remarked that their spiritual beliefs were their main way of coping.

On a final note, it is recommended that future longitudinal study should be conducted using random sampling and preferably to recruit participants from the onset (that is, diagnosis) of the disease to:

1. Examine the causal relationships between the QoL domains depicted by the revised Wilson and Cleary model using similar population.
2. Use independent measures to assess stigma, emotional distress, spirituality, future etc in a combination with the PROQOL-HIV to see if they will significantly relate to global PROQOL-HIV score as a measure of overall QoL.

References

- Abasiubong F, Ekott JU, Bassey EA, Etukumana EA & Edyang-Ekpa M (2010) 'Quality of life in people living with HIV/AIDS in Niger Delta Region, Nigeria' *Journal of Mental Health* 19 (2): 211-218
- Abasiubong F, Udoh SB, Idung AU & Umoiyoho AJ (2012) 'Attitudes and sexual behaviours of unmarried people with HIV/AIDS living in the Niger Delta region of Nigeria' *Mental Health in Family Medicine* 9 (4): 225-232
- Abegaz B (2005) *Ethiopia: A model nation of minorities*. Available at: <http://bxabeg.people.wm.edu/Ethiopia.Census%20Portrait.pdf> [accessed on 10/06/2017]
- Abu-Rmeileh NME, Hammoudeh W, Mataria A, Hussein A, Khawaja M, Shannon HS, Hogan D, Watt GCM, Zurayk H & Giacaman R (2011) Health-related Quality of life of Gaza Palestinians in the aftermath of the winter 2008-09 Israeli attack on the Strip. *European Journal of Public Health* 22 (5) 732-737
- Abramowitz M & Stegun (eds) (1964) *Handbook of mathematical functions with formulas, graphs and mathematical tables, NBS applied mathematical series 55*. Washington DC, National Bureau of Standards
- Abu-Saeed MB & Abu-Saeed K (2013) 'Attitudinal Changes Using Peer Education Training in the Prevention of HIV/AIDS: A Case Study of Youths in North Central Nigeria' *Advanced Pharmaceutical Bulletin* 3 (1): 45-50
- Adedimeji AA, Alawode OO & Odutolu O (2010) 'Impact of Care and Social Support on Well-being among people living with HIV/AIDS in Nigeria' *Iranian Journal of Public Health* 39 (2): 30-38
- Adewuya AO, Afolabi MO, Ola BA, Ogundele OA, Ajibare AO, Oladipo BF & Fakande I (2008) 'Relationship between depression and quality of life in persons with HIV Infection in Nigeria' *The International Journal of Psychiatry in Medicine* 38 (1): 43-51
- Ahern KJ (1999) 'Ten tips for reflexive bracketing' *Qualitative Health Research* 9(3): 407- 411
- Ahonkhai AA, Bassett IV, Ferris TG & Freedberg KA (2012) 'Improving HIV outcomes in resource-limited countries: the importance of quality indicators' *BMC Health Services Research* 12 (427): 1-12
- Ajayi B, Moses A, Gashau W & Omotara B (2013) 'Assessment of knowledge, perception and attitude of people living with HIV/AIDS towards HIV/AIDS in Maiduguri, Northeast Nigeria' *The international Journal of Infectious Diseases* 12(1): 1382 - 1390
- Akinboro AO, Akinyemi SO, Olaitan PB, Raji AA, Popoola AA, Awoyemi OR & Ayodele OE (2014) 'Quality of life of Nigerians living with human immunodeficiency virus' *The Pan African Medical Journal* 18: 234 doi: 10.11604/pamj.2014.18.234.2816
- Aliyu SU, Chiroma AS, Jajere AM & Gujba FK (2015) 'Prevalence of physical inactivity, hypertension, obesity and tobacco smoking: A case of NCDs prevention among adults in Maiduguri, Nigeria' *American Journal of Medical Sciences and Medicine* 3(4): 39-47
- Aljazeera (2011) *Nigerian city rocked by new blasts*. Aljazeera new, Available at: <http://www.aljazeera.com/news/africa/2011/06/201162621858898349.html> [Accessed on 15/04/2016]
- Allen PJ & Bennett K (2012) *SPSS statistics: A practical guide version 20*. Cengage Learning Australia Pty Ltd, South Melbourne

- Alomepe J, Buseh AG, Awasom C, Snethen JA (2016) 'Life with HIV: Insights from HIV-infected women in Cameroon, Central Africa' *Journal of the Association of Nurses in AIDS Care* 27 (5): 654-666
- A Moran OE (2012) 'Predictors of disclosure of sero-status to sexual partners among people living with HIV/AIDS in Ogun State, Nigeria' *Nigerian Journal of Clinical Practice* 15 (4): 385-390
- Anderson KL & Burckhardt CS (1999) 'Conceptualization and measurement of quality of life as an outcome variable for health care intervention and research' *Journal of Adverse Nursing* 29(2): 298-306
- Andrinopoulos K, Clum G, Murphy DA, Harper G, Perez L, Xu J, Cunningham S, Ellen JM & Adolescent Medicine Trials Network for HIV/AIDS Interventions (2011) 'Health related quality of life and psychosocial correlates among HIV-infected adolescent and young adult women in the US' *AIDS Education & Prevention* 23 (4): 367-381
- Anema A, Joffres MR, Mills E & Spiegel PB (2008) 'Widespread rape does not directly appear to increase the overall HIV prevalence in conflict-affected countries: so now what?' *Emerging Themes in Epidemiology* 5:11 doi:10.1186/1742-7622-5-11
- Ansari DA & Gaestel A (2010) 'Senegalese religious leaders' perceptions of HIV/AIDS and implications for challenging stigma and discrimination' *Culture, Health & Sexuality* 12 (6): 633-648
- Archer MS (2012) *The reflexive imperative in late modernity*. New York: Cambridge University Press
- Arnold R, Ranchor AV, Koeter GH, de Jongste MJ & Sanderman R (2005) 'Consequences of chronic obstructive pulmonary disease and chronic heart failure: the relationship between objective and subjective health' *Social Science & Medicine* 61(10): 2144-2154
- Atuyambe L, Neema S, Otolok-Tanga E, Wamuyu-Maina G, Kasasa S, & Wabwire-Mangen F (2008) 'The effects of enhanced access to antiretroviral therapy: a qualitative study of community perceptions in Kampala city, Uganda' *African Health Sciences* 8 (1): 13 – 19
- Aveyard H (2010) *Doing a literature review in health and social care: A practical guide* McGraw-Hill
- Aziz IA, Hutchinson CV & Maltby J (2014) 'Quality of life of Syrian refugees living in camps in the Kurdistan Region of Iraq' *PeerJ* 2: e670. doi: 10.7717/peerj.670
- Bakas T, McLennon SM, Carpenter JS, Buelow JM, Otte JL, Hanna KM, Ellett ML, Hadler KA & Welch JL (2012) 'Systematic review of health-related quality of life models' *Health & Quality of Life Outcomes* 10 (134): 1-25
- Balderson BH, Grothaus L, Harrison RG, McCoy K, Mahoney C & Catz S (2013) 'Chronic illness burden and quality of life in an aging HIV population' *AIDS Care* 25(4): 451-458
- Bandalos DL (2008) 'Is parceling really necessary? A comparison from item parceling and categorical variable methodology' *Structural Equation Modelling* 15: 211 – 240
- Bangdiwala SI, Fonn S, Okoye O & Tollman S (2010) 'Workforce resources for health in developing countries' *Public Health Reviews* 32: 296-318
- Barroso J & Powell-Cope GM (2000) 'Metasynthesis of qualitative research on living with HIV infection' *Quality of Health Research* 10: 340-352

- Bazeley P (2004) Issues in mixing qualitative and quantitative approaches to research In: Buber R, Gadner J & Richards L (eds) *Applying qualitative methods to marketing management research*. London, Palgrave Macmillan
- Brännulund A, Hammarström A, & Strandh M (2013) 'Education and health-behaviour among men and women in Sweden: A 27-year prospective cohort study' *Scandinavian Journal of Public health* 41(3): 284-292
- Belak Kovacevic S, Vurusic T, Duvancic K & Macek M (2006) 'Quality of life of HIV-infected persons in Croatia' *Collegium Antropologicum* 30 (Suppl 2) 79–84
- Bello SI & Bello IK (2013) 'Quality of life of HIV/AIDS patients in a secondary health care facility, Ilorin, Nigeria' *Baylor University Medical Center Proceedings* 26 (2): 116-11
- Bezabhe WM, Chalmers L, Bereznicki LR, Peterson GM, Bimirew MA & Kassie DM (2014) 'Barriers and facilitators of adherence to antiretroviral drug therapy and retention in care among adult HIV-positive patients: A qualitative study from Ethiopia' *PLoS ONE* 9 (5): e97353. doi:10.1371/journal.pone.0097353
- BBC (2015) *Boko Haram crisis: Nigerian military chiefs given deadline*. BBC News. Available at: <http://www.bbc.co.uk/news/world-africa-33913305> [Accessed on 15/04/2016]
- Beuscher L & Grando VT (2009) 'Using spirituality to cope with early-stage Alzheimer's disease' *Western Journal of Nursing Research* 31(5): 583-598
- Bishop AJ, Martin P, Poon L & Johnson MA (2011) 'Exploring positive and negative affect as key Indicators of life satisfaction among centenarians: Does cognitive performance Matter?' *Journal of Aging Research* Article ID 953031, doi:10.4061/2011/953031
- Bjordal JM, Bogen B, Lopes-Martins RA & Klovning A (2005) 'Can Cochrane Reviews in controversial areas be biased? A sensitivity analysis based on the protocol of a Systematic Cochrane Review on low-level laser therapy in osteoarthritis' *Photomedicine & Laser Surgery* 23 (5): 453-458
- Blaikie N (2009) *Analyzing quantitative data: From description to explanation*. London: Sage
- Blunch NJ (2013) *Introduction to structural equation modelling using IBM SPSS statistics and Amos (2nd ed)*. Sage Los Angeles 77-162
- Brent RJ (2012) 'The effects of HIV medications on the quality of life of older adults in New York City' *Health Economics* 21 (8): 967-976
- Bryman A & Cramer D (1990) *Quantitative data analysis for social scientist*. London: Routledge
- Booth ML (2000) 'Assessment of of physical activity: An international perspective' *Research Quarterly for Exercise & Sport* 17 (2):s114-120
- Brown TT & Glesby MJ (2011) 'Management of the metabolic effects of HIV and HIV drugs' *Nature Review Endocrinology* 8 (1): 11-2
- Bowling A & Ebrahim S (ed) (2007) *Handbook of health research methods: Investigation, measurement and analysis* London: Open University Press
- Bowling A (2009) *Research methods in health: Investigating health and health services* (3rd edition). Buckingham: Open University Press

- Bowling A (2002) *Research methods in health: Investigating health and health services* (2nd edition). Buckingham: Open University Press
- Bowling A (2017) *Measuring health: A review of subjective health, well-being and quality of life measurement scales* (4th edition). Philadelphia: Open University Press
- Bowling Ann & Windsor, Joy (2001) 'Towards the good life: A population survey of dimensions of quality of life' *Journal of Happiness Studies* 2 (1): 55-82
- Boyce C & Neale P (2006) *Conducting In-depth interviews: A Guide for Designing and Conducting In-depth Interviews for Evaluation Input*. Available at: http://www.pathfind.org/site/DocServer/m_e_tool_series_indepth_interviews.pdf?docID=6301 [Accessed on 31/07/2013]
- Brink HI, Van der Walt C, Van Rensburg G (2006) *Fundamentals of research methodology for health care professionals (2nd edn)*. Cape Town, Juta
- Brookings JB & Bolton B (1988) 'Confirmatory factor analysis of the Interpersonal Support Evaluation List' *American Journal of Community Psychology* 16, 137-147
- Bryman A (2012) *Social research method (3rd edn)*. Oxford, Oxford University Press
- Bryman B & Bell E (2011) *Business Research Methods* (3rd edition). Oxford: Oxford University Press
- Bryman A & Burgess RG [eds.] (1994) *Analyzing qualitative data*. London, Routledge
- Bryman A & Cramer D (1990) *Quantitative Data Analysis for Social Scientists* London, Routledge
- Buchanan DR (1998) 'Beyond positivism: Humanistic perspectives on theory and research in health education' *Health Education Research* 13 (3): 439-450
- Burns N & Grove SK (2005) *The practice of nursing research: Conduct, critique and utilization (5th ed)*. St Louis, ELSEVIER
- Caruana EJ, Roman M, Hernández-Sánchez J & Solli P (2015) 'Longitudinal studies' *Journal of Thoracic Diseases* 7(11): E537–E540
- Chadambuka A, Katirayi L, Muchedzi A, Tumbare E, Musarandega R, Mahomva AI & Woelk G (2017) 'Acceptability of lifelong treatment among HIV-positive pregnant and breastfeeding women (Option B+) in selected health facilities in Zimbabwe: a qualitative study' *BMC Public Health* 18: 57
- Chang T-S, Chang C-M, Ho H-C, Su Y-C, Chen L-F, Chou P & Lee C-C (2013) 'Impact of young age on the prognosis for oral cancer: A population-based study in Taiwan' *PLoS ONE* 8 (9): e75855 doi:10.1371/journal.pone.0075855
- Calabrese Barton A (1998) *Feminist science education*. New York, Teachers College Press
- Cameron R (2009) 'A sequential mixed model research design: Design, analytical and display issues' *International Journal of Multiple Research Approaches* (3) 2 140–152
- Cameroon Demographic and Health Survey (2011) *Prevalence of HIV in Cameroon: Findings from the 2011 Demographic and Health Survey- Multiple indicator cluster survey*. Yaoundé, Cameroon Available at: <https://dhsprogram.com/pubs/pdf/HF42/HF42.pdf> Accessed on 14/04/2017

Carballo E, Cadarso-Suárez C, Carrera I, Fraga J, de la Fuente J, Ocampo A, Ojea R & Prieto A (2004) 'Assessing relationships between health-related quality of life and adherence to antiretroviral therapy' *Quality of Life Research* 13 (3): 587-599

Carlson MDA & Morrison RS (2009) 'Study design, precision, and validity in observational studies' *Journal of Palliative Medicine* 12 (1) 77–82

Carta MG, Aguglia E, Caraci F, Dell'Osso L, Di Sciascio G, Drago F, Del Giudice E, Faravelli C, Hardoy MC, Lecca ME, Moro MF, Calò S, Casacchia M, Angermeyer MC & Balestrieri M (2012) 'Quality of Life and Urban / Rural Living: Preliminary Results of a Community Survey in Italy' *Clinical Practice & Epidemiology in Mental Health* 8: 169–174

Cederfjäll C, Langius-Eklöf A, Lidman K & Wredling R (2001) 'Sex difference in perceived health-related quality of life among patients with HIV infection' *AIDS Patient Care STDS* 15 (1): 31-39

Central Statistical Agency (2012) *2011 Ethiopian demographic and health survey: Technical report. Addis Ababa*. CSA Available at: <http://www.csa.gov.et/index.php/census-report/census-tables/category/301-census-tables> [accessed on 10/06/2017]

Chama C, Mairiga A, Geidam A & Bako B (2010) 'An assessment of policies and programs for reducing maternal mortality in Borno State, Nigeria' *African Journal of Reproductive Health (Special Issue)* 14 (3): 49

Chambers LA, Rueda S, Baker DN, Wilson MG, Deutsch R, Raeifar E, Rourke SB & The Stigma Review Team (2015) 'Stigma, HIV and health: a qualitative synthesis' *BMC Public Health* 15: 848 DOI: 10.1186/s12889-015-2197-0

Charles B, Jeyaseelan L, Pandian AK, Sam AE, Thenmozhi M & Jayaseelan V (2012) 'Association between stigma depression and quality of life of people living with HIV/AIDS (PLHA) in South India - a community based cross sectional study' *BMC Public Health* 12: 463

Chaudoir SR, Norton WE, Earnshaw VA, Moneyham L, Mugavero MJ & Hiers KM (2012) 'Coping with HIV stigma: Do proactive coping and spiritual peace buffer the effect of stigma on depression?' *AIDS and Behavior* 16 (6) 2382-2391

Chavez C (2008) 'Conceptualising from the inside: Advantages, complications, and demands on insider positionality' *The Qualitative Report* 13(3): 474 – 494

Chen W, Shiu C, Simoni JM, Zhao H, Bao JM & Lu H (2011) 'In sickness and in health: A qualitative study of how Chinese women with HIV navigate stigma and negotiate Disclosure within their Marriages/Partnerships' *AIDS Care* 23 (Suppl 1): 120–125

Chia L (2007) *The characteristics that associate with health-related quality of life in patients with type-2 diabetes* PhD Thesis. University of Pittsburgh

Čisar & Čisar (2010) 'Skewness and kurtosis in function of selection of network traffic distribution' *Acta Polytechnica Hungarica* 7(2) 95-106

Ciccolo JT, Jowers EM & Bartholomew JB (2004) 'The benefits of exercise training for quality of life in HIV/AIDS in the post-HAART era' *Sports Medicine* 34 (8): 487-499

Claussen C (2004) 'Using quality of life measures for program evaluation: A review of the literature' *Rehabilitation Review* 15 (1) Available at: http://www.acds.ca/PDF/Outcome%20Evaluations/MTD_Module_5_INSERT_2_QOL_Indicators.pdf [Accessed on 24/09/2013]

- Clayson D, Wild D, Quarterman P, Duprat-Lomon I, Kubin M & Coons S (2006) 'A comparative review of the health-related quality-of-life measures for use in HIV/AIDS clinical trials' *Pharmacoeconomics* 24 (8): 751–765
- Clingerman E (2004) 'Physical activity social support and health-related quality of life among persons with HIV disease' *Journal of Community Health Nursing* 21 (3): 179-197
- Cohen D & Crabtree B (2006) *Qualitative research guidelines project*. Princeton, New York Available at: <http://www.qualires.org/HomeRefl-3703.html> [accessed 19/01/18]
- Cohen L, Manion L, Morrison K (2011) *Surveys, longitudinal, cross-sectional and trend studies in research methods in education* (7th edn). London, Routledge
- Combs JP & Onwuegbuzie AJ (2010) Describing and illustrating data analysis in mixed research. *International Journal of Education* 2 (2) E13
- Cooper V, Moyle GJ, Fisher M, Reilly G, Ewan J, Liu HC, Horne R & SWEET (Simplification With Easier Emtricitabine Tenofovir) group UK (2011) 'Beliefs about antiretroviral therapy treatment adherence and quality of life in a 48-week randomised study of continuation of zidovudine/lamivudine or switch to tenofovir DF/emtricitabine each with efavirenz' *AIDS Care* 23 (6): 705-713
- Cosby C, Holzemer WL, Henry SB & Portillo CJ (2000) 'Hematological complications and quality of life in hospitalized AIDS patients' *AIDS Patient Care & STDs* 14 (5): 269-279
- Côté J, Delmas P, Delpierre C, Sylvain H, Delon S & Rouleau G (2009) 'Factors related to quality of life in treatment-adherent, successfully treated HIV patients in France' *The Open Nursing Journal* 3: 10-17
- Creswell JW (2014) *Research design: Qualitative, quantitative, and mixed methods approaches* (4th edition). London, SAGE
- Creswell JW (2013) *Qualitative inquiry and research design: Choosing among five approaches* (3rd edition). London, SAGE
- Creswell JW & Plano Clark VL (2010) *Designing and conducting mixed methods research*. London, SAGE Publication
- Creswell J (2008) *Educational research: Planning, conducting, and evaluating quantitative and qualitative research (3rd ed)*. Upper Saddle River, NJ: Pearson Education
- Creswell JW, Plano Clark V L, Garrett A (2010) Methodological issues in conducting mixed methods research designs. In: Bergman MM (ed) *Advances in mixed methods research: Theories and applications*. London, Sage
- Creswell J (2008) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 3rd edition Thousand Oaks, California Sage
- Creswell JW, Plano Clark VL, Gutmann ML, Hanson WE (2003) Advanced mixed methods research designs. In: Tashakkori A& Teddlie C (eds) *Handbook of mixed methods in social and behavioral research*. Thousand Oaks, CA: Sage
- Crotty M (1998) *The foundations of social science research: Meaning and perspective in the research Process*. London: SAGE
- Culbert H, Tu D, O'Brien DP, Ellman T, Mills C, Ford N, Amisi T, Chan K, Venis S & Médecins Sans Frontières (2007) 'HIV treatment in a conflict setting: outcomes and experiences from Bukavu, Democratic Republic of the Congo' *PLoS Medicine* 4: e129

Cunningham GR, Stephens-Shields AJ, Rosen RC, Wang C, Ellenberg SS, Matsumoto AM, Bhasin S, Molitch ME, Farrar JT, Cella D, Barrett-Connor E, Cauley JA, Cifelli D, Crandall JP, Ensrud KE, Fluharty L, Gill TM, Lewis CE, Pahor M, Resnick SM, Storer TW, Swerdloff RS, Anton S, Basaria S, Diem S, Tabatabaie V, Hou X, & Snyder PJ (2015) 'Association of sex hormones with sexual function, vitality, and physical function of symptomatic older men with low testosterone levels at baseline in the testosterone trials' *Journal of Clinical Endocrinology & Metabolism* (2015) 100 (3): 1146-1155

Danielewicz J (2001) *Teaching selves: identity, pedagogy and teacher education* Albany. New York, SUNY Press

da Cunha J, Maselli LM, Stern AC, Spada C & Bydlowski SP (2015) 'Impact of antiretroviral therapy on lipid metabolism of human immunodeficiency virus-infected patients: Old and new drugs' *World Journal of Virology* 4 (2): 56-77

Darlaston-jones D (2007) 'Making connections: The relationship between epistemology and research methods' *Australian Community Psychologist* 19 (1): 19-27

Davis KC, Schraufnagel TJ, Kajumulo KF, Gilmore AK, Norris J & George WH (2014) 'A qualitative examination of men's condom use attitudes and resistance: "It's just a part of the game"' *Archives of Sexual Behaviour* 43(3): 631-643

De Boudeaudhuij I, Sallis JF & Saelens BE (2003) 'Environmental correlates of physical activity in a sample of Belgium adults' *American Journal of Health Promotion* 8 (1): 83-92

DeLyser D (2001) "'Do you really live here?'" Thoughts on insider research' *Geographical Review* 91(1/2): 441-453

Denzin NK & Lincoln YS (eds) (2000) *Handbook of Qualitative Research* (2nd edition). London: Sage Publications

Deribew A, Tesfaye M, Hailmichael Y, Negussu N, Daba S, Wogi A, Belachew T, Apers L & Colebunders R (2009) 'Tuberculosis and HIV co-infection: Its impact on quality of life' *Health Quality of Life Outcomes* 7: 105

de Silva AC, Reis RK, Nogueira JA, Gir E (2014) 'Quality of life, clinical characteristics and treatment adherence of people living with HIV/AIDS' *Revista Latino-Americana de Enfermagem* 22 (6): 994-1000

de Waal A (2010) 'Reframing governance, security and conflict in the light of HIV/AIDS: a synthesis of findings from the AIDS, Security and Conflict Initiative' *Social Science & Medicine* 70 (1): 114-120

Dibb B & Kamallesh T (2012) 'Exploring positive adjustment in HIV positive African women living in the UK' *AIDS Care* 24 (1-2): 143-148

Dixon-Woods M (2011) 'Using framework-based synthesis for conducting reviews of qualitative studies' *BMC Medicine* 9: 39 DOI: 10.1186/1741-7015-9-39

Douek DC, Brenchley JM, Betts MR, Ambrozak DR, Hill BJ, Okamoto Y, Casazza JP, Kuruppu J, Kunstman K, Wolinsky S, Grossman Z, Dybul M, Oxenius A, Price DA, Connors M & Koup RA (2002) 'HIV preferentially infects HIV-specific CD4+ T cells' *Nature* 417 (6884): 95-98

Driscoll DL, Appiah-Yeboah A, Salib P & Rupert DJ (2007) 'Merging qualitative and quantitative data in mixed methods research: How to and why not' *Ecological & Environmental Anthropology* 3 (1): 19-28

Duracinsky M, Herrmann S, Berzins B, Armstrong AR, Kohli R, Le Coeur S, Diouf A, Fournier I, Schechter M & Chassany O (2012a) 'The development of PROQOL-HIV: An international instrument to assess the health-related quality of life of persons living with HIV/AIDS' *Journal of Acquired Immune Deficiency Syndromes* 59 (5): 498-505

Duracinsky M, Lalanne C, Le Coeur S, Herrmann S, Berzins B, Armstrong AR, Lau JT, Fournier I & Chassany O (2012b) 'Psychometric validation of the PROQOL-HIV questionnaire: A New health-related quality of life instrument-specific to HIV disease' *Journal of Acquired Immune Deficiency Syndromes* 59 (5): 505-515

Echenberg M (2006) Historical perspectives on HIV/AIDS: lessons from South Africa and Senegal. In: Denis P & Becker C (eds.) *The HIV/AIDS epidemic in sub-Saharan Africa in a historical perspective*. Dakar, Senegal, Senegalese Network: Law, Ethics, Health

Eyler AE, Wilcox S, Matson-Koffman D, Evenson KR, Sanderson B, Thompson J, Wilbur J, & Rohm-Young D (2002) 'Correlates of physical activity among women from diverse racial/ethnic group' *Journal of Womens Health & Sex Based Medicine* 11 (3): 239-253

Ekure EN, Esezobor CI, Balogun MR, Woo JG, Mukhtar-Yola M, Ojo OO, Emodi IJ, Omoigberale AI Omoigberale AI, Ezechukwu C, Olowu AO, Ogala WN & Esangbedo DO (2013) 'Paediatrician workforce in Nigeria and impact on child health' *Nigerian Journal of Paediatrics* 40 (2): 112-118

Emery CF, Frid DJ, Engebretson TO, Alonzo AA, Fish A, Ferketich AK, Reynolds NR, Dujardin JP, Homan JE, Stern SL (2004) 'Sex Differences in quality of life among cardiac patients' *Psychosomatic Medicine* 66 (2) 190-197

Enwereji EE (2008) 'Sexual behaviour and inheritance rights among HIV- positive women in Abia State' *Tanzania Journal of Health Research* 10 (2): 73 -78

Errihani H, Mrabti H, Boutayeb S, El Ghissassi I, El Mesbahi O, Hammoudi M, Chergui H, Riadi A (2008) 'Impact of cancer on Moslem patients in Morocco' *Psycho- Oncology* 17 (1): 98-100

European Affairs (2017) *Borno records 3800 new cases of HIV in IDPs camps*. Guidonia Montecelio, EA Available at: <http://www.europeanaffairs.media/2017/04/06/orno-records-3800-new-cases-hiv-idps-camps/> [accessed on 1/05/2017]

EuroQolGroup (1990) 'EuroQol – a new facility for the measurement of health-related quality of life' *Health Policy* 16: 199–208

Ezeamama AE, Woolfork MN, Guwatudde D, Bagenda D, Manabe YC, Fawzi WW & Smith-Fawzi MC (2016) 'Depressive and anxiety symptoms predict sustained quality of life deficits in HIV-positive Ugandan adults despite antiretroviral therapy' *Medicine* 95 (9): e2525 doi.10.1097/MD.0000000000002525

Ezechi OC, Gab-Okafor CV, Ostergren PO & Pettersson KO (2013) 'Willingness and acceptability of cervical cancer screening among HIV positive Nigerian women' *BMC Public Health* 13 (46): 1-8

Family Health International (2015) *Assessment of HIV/AIDS services in IDP camps in Borno State*. Durham, FHI-360 Available at: <https://www.fhi360.org/sites/default/files/media/documents/resource-sidhas-idp-camp-assessment-report.pdf> [accessed on 1/05/2017]

- Fatasi AO (2005) 'Adolescent sexual and reproductive health needs in Nigeria: shaping a pragmatic and effective response' *Journal of Community Medicine and Primary Health Care* 17: 1–6
- Fatiregun AA, Mofolorunsho KC & Osagbemi KG (2009) 'Quality of life of people living with HIV/AIDS in Kogi State, Nigeria' *Benin Journal of Postgraduate Medicine* 11 (1): 21-27
- Federal Ministry of Health (2011) *Technical report on the 2010 national HIV sentinel survey among pregnant women attending antenatal clinics in Nigeria*. Abuja, FMOH Available at: http://www.nigeria-aids.org/documents/2010_National%20HIV%20Sero%20Prevalence%20Sentinel%20Survey.pdf [Accessed on 06/01/2013]
- Federal Ministry of Health (2010a) *National strategic health development plan 2010–2015*. Abuja, FMOH Available at: <http://www.whiteribbonalliance.org/index.cfm/reports/national-strategic-health-development-plan-2010-2015/> [Accessed on 05/01/2013]
- Federal Ministry of Health (2010b) *National policy on infant and young child feeding*. Abuja, FMOH Available at: <http://www.health.gov.ng/doc/IYCFPolicy.pdf> [Accessed on 07/08/2016]
- Federal Ministry of Health (2006) *Nigerian national blood policy 2005*. Abuja, FMOH
- Federal Ministry of Health of Nigeria (2005) *Health promotion policy 2005 for Nigeria*. Abuja, FMOH Available at: http://www.fmh.gov.ng/images/PolicyDoc/FMOH_Health_Promotion_Policy.pdf [Accessed on 06/01/2013]
- Federal Ministry of Labour and Productivity (2013) *National Workplace Policy on HIV and AIDS 2013*. Abuja, FMO/LPE Available at: http://www.ilo.org/wcmsp5/groups/public/---africa/--ro-addis_ababa/---ilo-abuja/documents/publication/wcms_344217.pdf [Accessed on 2/06/2017]
- Ferrans CE & Powers MJ (1992) 'Psychometric assessment of the Quality of Life Index' *Research in Nursing & Health* 15 (1): 29-38
- Ferrans CE, Zerwic JJ, Wilbur JE & Larson JL (2005) 'Conceptual model of health-related quality of life' *Journal of Nursing Scholarship* 37 (4): 336-342
- Flowerdew R & Martin DM (2005) *Methods in Human Geography: A guide for students doing a research project*. Routledge Taylor & Francis, London
- Fletcher JM & Frivold DE (2009) 'Higher education and health investment: Does more schooling affect preventive health care use?' *Journal of Human Capital* 3(2): 144-174
- Folasire OF, Akinyemi O & Owoaje E (2014) 'Perceived social support among HIV positive and HIV negative people in Ibadan, Nigeria' *World Journal of AIDS* 4: 15-26
- Folasire OF, Irabor AE & Folasire AM (2012) 'Quality of life of people living with HIV and AIDS attending the Antiretroviral Clinic University College Hospital, Nigeria' *African Journal of Primary Health Care & Family Medicine* 4 (1): 1-8
- Folayan M (2004) HIV/AIDS: The Nigerian response. In: Poku N & Whiteside A (eds) *The Political Economy of AIDS in Africa*. Aldershot: Ashgate Press
- Franco S, Suarez CM, Naranjo CB, Báez LC & Roza p (2006) 'The effects of the armed conflict on the life and health in Colombia' *Ciência & Saúde Coletiva*, 11(2): 349-361

- Fuller T & Loogma K (2009) 'Constructing futures: A social constructionist perspective on foresight methodology' *Futures* 41 (2): 71–79
- Galantino ML, Shepard K, Krafft L, LaPerriere A, Ducette J, Sorbello A, Barnish M, Condoluci D & Farrar JT (2005) 'The Effect of Group Aerobic Exercise and *T'ai Chi* on functional outcomes and quality of life for persons living with acquired immunodeficiency syndrome' *The Journal of Alternative & Complementary Medicine* 11 (6): 1085–1092
- Gale NK, Heath G, Cameron E, Rashid S & Redwood S (2013) 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research' *BMC Medical Research Methodology* 13 (117): 1-8
- Garang PG, Odoi RA & Kalyango JN (2009) 'Adherence to antiretroviral therapy in conflict areas: a study among patients receiving treatment from Lacor Hospital, Uganda' *AIDS Patient Care & STDs* 23 (9): 743-747
- Garbati MA, Abba AA, Kabrang DN & Yusuph H (2011) 'HIV/AIDS in North-eastern Nigeria: a review' *Journal of Infectious Diseases & Immunity* 3 (10): 176-182
- Gard TL, Hoover DR, Shi Q, Cohen MH, Mutimura E, Adedimeji AA & Anastos K (2013) The impact of HIV status, HIV disease progression and post-traumatic stress symptoms on the health-related quality of life of Rwandan women genocide survivors. *Quality of Life Research* 22 (8) 2073–2084
- Garratt A, Schmidt L, Mackintosh A & Fitzpatrick R (2002) 'Quality of life measurement: Bibliographic study of patient assessed health outcome measures. *British Medical Journal* 324 (7351): 1417
- Garvie PA, Lawford J, Banet MS & West RL (2009) 'Quality of life measurement in paediatric and adolescent populations with HIV: A review of the literature' *Child: Care Health & Development* 35 (4): 440-453
- Geurtsen B (2005) 'Quality of life and living with HIV/AIDS in Cambodia' *Journal of Transcultural Nursing* 16 (1): 41-49
- Ghinia I, Willott C, Dadari I & Larson HJ (2013) 'Listening to the rumours: What the northern Nigeria polio vaccine can tell us ten years on' *Global Public Health* 8(10): 1138-1150
- Gomes Neto M, Conceição CS, Carvalho VO & Brites C (2015) 'Effects of combined aerobic and resistance exercise on exercise capacity, muscle strength and quality of life in HIV-infected patients: A systematic review and meta-analysis. *PLoS ONE* 10 (9): 1-14
- Gorecki C, Brown JM, Cano S, Lamping DL, Briggs M, Coleman S, Dealey C, McGinnis E, Nelson AE, Stubbs N, Wilson L & Nixon J (2013) 'Development and validation of a new patient-reported outcome measure for patients with pressure ulcers: The PU-QOL instrument' *Health and Quality of Life Outcomes* 11: 95 doi:10.1186/1477-7525-11-95
- Gort JD, Jansen H & Vroom HM (ed) (2002) *Religion, conflict and reconciliation: Multifaith ideals and realities*. Amsterdam, Rodopi B.V
- Graneheim UH & Lundman B (2004) 'Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness' *Nurse Education Today* 24 (2): 105-112
- Green J & Thorogood N (2006) *Qualitative methods for health research*. London, SAGE Publication

- Griffiths K & Ford N (2013) 'Provision of antiretroviral care to displaced populations in humanitarian settings: a systematic review' *Medicine, Conflict & Survival* 29 (3): 198-215
- Griffiths F (2009) *Research method for health care practice* London: SAGE
- Groft JN & Robinson VA (2007) 'Seeking serenity: Living with HIV/AIDS in rural Western Canada' *Rural & Remote Health* 7 (677): 1-11
- Grudem W (1994) *Systematic Theology*. Leicester, Intervarsity Press
- Guaraldi G, Stentarelli C, Zona S, Santoro A, Beghetto B, Carli F, Orlando G, Franceschetto A, Casolo A & Mussini C (2014) 'The natural history of HIV-associated lipodystrophy in the changing scenario of HIV infection' *HIV Medicine* 15 (10): 587-594
- Gupta B & Kant S (2008) 'Health related quality of life (HRQOL) in COPD' *The Internet Journal of Pulmonary Medicine* 11 (1): Available at: <http://ispub.com/IJPM/11/1> [Accessed on 21/11/2013]
- Gakahu N & Kaguta RJN (2011) 'Communicating HIV & AIDS among students in Kenya's institutions of higher learning: A challenge for the 21st century' *Journal of Economics and Sustainable Development* 2 (4): 171-174
- Hammoudeh W, Hogan D & Giacaman R (2013) 'Quality of life, human insecurity, and distress among Palestinians in the Gaza Strip before and after the Winter 2008-2009 Israeli war' *Quality of Life Research* 2013 22 (9): 2371-237
- Hancock B, Windridge K, Ockleford E (2007) *An introduction to qualitative research*. The National Institute for Health Research-Research Design Services (NIHR RDS) East Midlands/Yorkshire Available at: http://www.rds-sc.nihr.ac.uk/wp-content/uploads/2011/07/5_Introduction-to-qualitative-research-20091.pdf [Accessed on 03/08/2013]
- Hand GA, Lysterly GW, Jagers JR & Dudgeon WD (2009) Impact of aerobic and resistance exercise on the health of HIV infected persons' *American Journal of Lifestyle & Medicine* 3(6): 489-499
- Hanson WE, Creswell JW, Plano Clark VL, Petska KS, Creswell JD (2005) Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology* 52 (2) 224-235
- Hasnain M, Levy JA, Mensah EK & Sinacore JM (2007) 'Association of educational attainment with HIV risk in African American active injection drug users' *AIDS Care* 19(1): 87-91
- Haywood KL (2006) 'Patient-reported outcome I: Measuring what matters in musculoskeletal care' *Musculoskeletal Care* 4: 187-203
- Health System Trust (ND) *HIV/AIDS drugs run out in Nigeria*. South Africa, HST Available at: <http://www.hst.org.za/news/hivaids-drugs-run-out-nigeria> [Accessed on 25/11/2013]
- Hellström I, Nolan M, Nordenfelt L & Lundh U (2007) 'Ethical and methodological issues in interviewing persons with dementia' *Nursing Ethics* 14 (5): 608-619
- Henderson WA, Martino AC, Kitamura N, Kim KH & Erlen JA (2012) 'Symptom status predicts patient outcomes in persons with HIV and comorbid liver disease' *AIDS Research and Treatment* 169645: 1-11

- Henderson WA, Fall-Dickson JM, Schlenk EA, Kim KH, Matthews JT & Erlen JA (2008) 'Effects of liver disease on the well-being of persons living with HIV' *The Journal of the Association of Nurses in AIDS Care* 19 (5): 368-374
- Herek GM, Widaman KF & Capitanio JP (2005) 'When sex equals AIDS: Symbolic stigma and heterosexual adults' inaccurate beliefs about sexual transmission of AIDS' *Social Problems* 52(1): 15-37
- Herrmann S, McKinnon E, Hyland NB, Lalanne C, Mallal S, Nolan D, Chassany O & Duracinsky M (2013) 'HIV-related stigma and physical symptoms have a persistent influence on health-related quality of life in Australians with HIV infection' *Health & Quality of Life Outcomes* 11: 56
- Hibberd FJ (2005) *Unfolding social constructionism*. New York, NY: Springer
- Higgins JPT & Green S (eds) (2011) *Cochrane handbook for Systematic Reviews of Interventions* (Version 5.1.0). The Cochrane Collaboration. Available at: www.cochrane-handbook.org [Accessed on 02/02/2013]
- Higgins JPT & Green S (2008) *Cochrane Handbook for Systematic Reviews of Interventions* (editors). Version 5.0.1
- Higginson IJ & Carr AJ (2001) 'Measuring quality of life: Using quality measures in the clinical setting' *British Medical Journal* 322 (7297): 1297-1300
- Hiribarren V (2017) *A history of Borno: Trans-Saharan African empire to failing Nigerian State* (1st ed). C Hurst Co Publishers Ltd, United Kingdom
- Hirst P & Wolley P (1982) *Social relations and human attributes*. London: Tavistock Publications
- Ho CF, Twinn S & Cheng KK (2010) 'Quality of life constructs of Chinese people living with HIV/AIDS' *Psychology Health & Medicine* 15 (2): 210-219
- Holstein JA & Gubrium JF (2003) Active interviewing. In: Gubrium JF & Holstein JA (Eds.), *Postmodern interviewing*. Thousand Oaks, CA: Sage
- Hooper D, Coughlan J & Mullen MR (2008) 'Structural equation modelling: Guidelines for determining model fit' *The Electronic Journal of Business Research Methods* 6 (1) 53 - 60
- Hopkins PE (2007) 'Positionalities and knowledge: Negotiating ethics in practice' *ACME: An International E-Journal for Critical Geographies* 6(3): 386-394
- Howitt D & Cramer D (2011) *Introduction to Research Methods in Psychology* (3rd edition). Pearson Education Limited, Harlow
- Hu LT & Bentler PM (1999) 'Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives' *Structural Equation Modeling* 6 (1) 1-55
- Hult JR, Wrubel J, Bränström R, Acree M & Moskowitz JT (2012) 'Disclosure and nondisclosure among people newly diagnosed with HIV: An analysis from a stress and coping perspective' *AIDS Patient Care & STDs* 26 (3): 181-190
- Hussen SA, Tsegaye M, Argaw MG, Andes K, Gilliard D & del Rio C (2014) 'Spirituality, social capital and service: Factors promoting resilience among Expert Patients living with HIV in Ethiopia' *Global Public Health* 9 (3): 286-298

- Ilebani OA & Fabusoro E (2011) 'Effects of community-based care for people living with HIV/AIDS on their well-being in Benue State, Nigeria' *Research Journal of Medical Sciences* 5, 294-304
- Ivankova NV (2013) 'Implementing quality criteria in designing and conducting a sequential QUAN → QUAL mixed methods study of student engagement with learning applied research methods online' *Journal of Mixed Methods Research* 20 (10) 1–27
- Ivankova NV, Creswell JW & Stick SL (2006) 'Using mixed-methods sequential explanatory design: From theory to practice' *Field Methods* 18 (1) 3–20
- Jackson P (1993) Changing ourselves: A geography of position In RJ Johnston, (ed). *The Challenge for Geography, A Changing World: A Changing Discipline*. Oxford: Blackwell Publishers
- Jaiyesimi AO, Sofela EA & Rufai AA (2007) 'Health related quality of life and its determinants in Nigerian breast cancer patients' *African Journal of Medicine & Medical Sciences* 36 (3): 259-265
- Janz, NK & Marshall HB (1984) 'The Health Belief Model: A decade later' *Health Education & Behavior* 11(1): 1–47
- Johnson RB, Onwuegbuzie AJ & Turner LA (2007) 'Toward a Definition of Mixed Methods Research' *Journal of Mixed Methods Research* 1: 112
- Johnson RB & Onwuegbuzie AJ (2004) 'Mixed methods research: A research paradigm whose time has come' *Educational Researcher* 33 (7) 14-26
- Justice AC, Holmes W, Gifford AL, Rabeneck L, Zackin R, Sinclair G, Weissman S, Neidig J, Marcus C, Chesney M, Cohn SE, Wu AW & Adult AIDS Clinical Trials Unit Outcomes Committee (2001) 'Development and validation of a self-completed HIV symptom index' *Journal of Clinical Epidemiology* 54 (Suppl 1): S77-90
- Kagee A, Remien RH, Berkman A, Hoffman S, Campos L & Swartz L (2011) 'Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward' *Global Public Health* (1): 83-97
- Kaler A, Angotti N & Ramaiya A (2016) 'They are looking just the same: Antiretroviral treatment as social danger in rural Malawi' *Social Science & Medicine* 169: 71-78
- Kelley-Gillespie N (2009) 'An integrated conceptual model of quality of life for older adults based on a synthesis of the literature. *Applied Research in Quality of life* 4 (3): 259–282
- Khan K, Kunz R, Kleijnen J & Antes G (2003) *Systematic reviews to support evidence-based medicine: how to review and apply findings of healthcare research*. London: Royal Society of Medicine
- Kiboneka A, Nyatia RJ, Nabiryo C, Olupot-Olupot P, Anema A, Cooper C & Mills E (2008) 'Pediatric HIV therapy in armed conflict' *AIDS* 22: 1097-1098
- Kiboneka A, Nyatia RJ, Nabiryo C, Anema A, Cooper CL, Fernandes KA, Montaner JSG, & Mills EJ (2009) 'Combination antiretroviral therapy in population affected by conflict: outcomes from large cohort in northern Uganda' *British Medical Journal* 338: b201
- Kingori C, Reece M, Obeng S, et al. (2012) 'Impact of internalized stigma on HIV prevention behaviors among HIV-infected individuals seeking HIV care in Kenya' *AIDS Patient Care & STDS* 26: 761–768

Kittikraisak W, Kingkaew P, Teerawattananon Y, Yothasamut J, Natesuwan S, Manosuthi W, Chongsuvivatwong V & Whitehead SJ (2012) Health related quality of life among patients with tuberculosis and HIV in Thailand' *PLoS One* 7 (1) e29775

Kring D (2008) *Using the revised Wilson and Cleary model to explore factors affecting quality of life in persons on hemodialysis*. PhD Thesis. The University of North Carolina

Kumar S, Mohanraj R, Rao D, Murray KR & Manhart LE (2015) 'Positive coping strategies and HIV-related stigma in South India' *AIDS Patient Care & STDs* 29 (3) 157-163

Kusow AM (2003) 'Beyond indigenous authenticity: Reflections on the insider/outsider debate in migration research' *Symbolic Interaction* 26(4): 591-599

Labarese RV (2002) 'The risk of 'going observationalist': Negotiating the hidden dilemmas of being insider participant observer' *Qualitative Research* 2(1): 97-122

Lalanne C, Chassany O, Carrieri P, Marcellin F, Armstrong AR, Lert F, Spire B, Dray-Spira R & Duracinsky M (2016) 'A reduced factor structure for the PROQOL-HIV questionnaire provided reliable indicators of health-related quality of life' *Journal of Clinical Epidemiology* 72: 116-125

Lapa TY (2015) 'Physical activity levels and psychological well-being: A case study of University students' *Procedia - Social & Behavioral Sciences* 186: 739 – 743

Lee M, Nezu AM, Nezu CM (2014) 'Positive and negative religious coping, depressive symptoms, and quality of life in people with HIV' *Journal of Behavioral Medicine* 37 (5): 921-930

Leserman J, Whetten K, Lowe K, Stangl D, Swartz MS & Thielman NM (2005) 'How trauma, recent stressful events, and PTSD affect functional health status and health utilization in HIV-infected patients in the south' *Psychosomatic Medicine* 67 (3) 500-507

Lei P & Wu Q (2007) *Introduction to structural equation modeling: Issues and practical considerations*. Educational Measurement: Issues & Practice, The University of Pennsylvania Available at: <http://ncme.org/linkservid/47EFEB5A-1320-5CAE-6EC90BFDF09AA39E/showMeta/0/> [Accessed on 16/07/2013]

Li X, Huang L, Wang H, Fennie KP, He G & Williams AB (2011) 'Stigma mediates the relationship between self-efficacy medication adherence and quality of life among people living with HIV/AIDS in China' *AIDS Patient Care STDs* 25 (11): 665-671

Lincoln YS & Guba EG (1985) *Naturalistic inquiry*. Beverly Hills, CA: SAGE

Lit S-W & Shek DTL (2007) 'Application of social constructionist principles in field practice teaching in a Chinese context' *Social Work Education: The International Journal* 26(4): 359-375

Lit S-W & Shek DTL (2002) 'Implications of social constructionism to counseling and social work practice' *Asian Journal of Counselling* 9 (1 & 2): 105–130

Little TD, Cunningham WA, Shahar G & Widaman KF (2002) 'To parcel or not to parcel: Exploring the question, weighing the merits' *Structural Equation Modelling* 9(2): 151–173

Liu H, Xu Y, Lin X, Shi J, Chen S (2013) 'Associations between perceived HIV stigma and quality of life at the Dyadic Level: The Actor-Partner Interdependence Model' *PLoS ONE* 8 (2): e55680. doi:10.1371

- Liu C, Ostrow D, Detels R, Hu Z, Johnson L, Kingsley L & Jacobson LP (2006a) 'Impacts of HIV infection and HAART use on quality of life' *Quality of Life Research* 15 (6): 941-949
- Liu C, Weber K, Robison E, Hu Z, Jacobson LP & Gange SJ (2006b) 'Assessing the effect of HAART on change in quality of life among HIV-infected women' *AIDS Research & Therapy* 20 (3): 6
- Lock A & Strong T (2010) *Social constructionism: Sources and stirrings in theory and practice*. Cambridge: Cambridge University Press
- Madru N (2003) 'Stigma and HIV: Does the social response affect the natural course of the epidemic?' *Journal of Association of Nurses in AIDS Care* 14(5): 39-48
- Maduforo AN, Ubah NC, Obiakor-Okeke PN (2013) 'The practice of exclusive breastfeeding by lactating women in Owerri metropolis, Imo State, Nigeria' *Global Advanced Research Journal of Medicine & Medical Sciences* 2 (1): 13-19
- Mahalakshmy T, Premarajan K & Hamide A (2011) 'Quality of life and its determinants in people living with human immunodeficiency virus infection in Puducherry, India' *Indian Journal of Community Medicine* 36 (3): 203-207
- Maher FA & Tetreault MK (1994) *The Feminist Classroom* New York Basic Books
- Maduagwu SM (2016) *Effect of exercise on the cardiovascular and lipid profiles of people living with HIV in Maiduguri, Nigeria*. PhD Thesis. University of Maiduguri
- Maiangwa B & Uzodike UO (2012) *The changing dynamics of Boko Haram terrorism: Report*. Al Jazeera Centre for Studies, Doha, Qatar Available at: <http://studies.aljazeera.net/mritems/Documents/2012/7/31/20127316843815734The%20Changing%20Dynamics%20of%20Boko%20Haram%20Terrorism.pdf> [Accessed 15/04/2016]
- Mairiga AG & Saleh W (2009) 'Maternal mortality at the state specialist hospital Bauchi, Northern Nigeria' *East African Medical Journal* 86 (1) 25-30
- Maman S, Abler L, Parker L, Lane T, Chirowodza A, Ntogwisangu J, Srirak N, Modiba P, Murima O & Fritz K (2009) 'A comparison of HIV stigma and discrimination in five international sites: the influence of care and treatment resources in high prevalence settings' *Social Science Medicine* 68(12): 2271-2278
- Manson SM (2008) 'Does scale exist? An epistemological scale continuum for complex human-environment systems' *Geoforum* 39 (2): 776-788
- Martin F, Russell S & Seeley J (2014) 'Higher quality of life and lower depression for people on ART in Uganda as compared to a community control group' *PLoS One* 9 (8):e105154
- Martin F, Turner AP, Wallace LM, Choudhry K & Bradbury N (2013) 'Perceived barriers to self-management for people with dementia in the early stages' *Dementia: The International Journal of Social Research & Practice* 12 (4): 481-493
- May T (2011) *Social research: Issues, methods and process* (4th edition). Maidenhead: The McGraw-Hill Education
- Mbada CE, Olaniyi Onayemi O, Ogunmoyole Y, Olubusola Esther Johnson OE & Akosile CO (2013) 'Health-related quality of life and physical functioning in people living with HIV/AIDS: a case-control design' *Health & Quality of Life Outcomes* 11:106
- McCance, KL & Huether SE (2006) *Pathophysiology: The biologic basis for disease in adults and children (5th ed)*. St. Louis, MO: Elsevier Mosby Company

- McClimans L (2010) 'A theoretical framework for patient-reported outcome measures' *Theoretical Medicine & Bioethics* 31 (3): 225-240
- McDougall I, Brown H & Fleagle G (2005) 'Stratigraphic placement and age of modern humans from Kibish, Ethiopia' *Nature* 433(7027): 733–736
- McDonnell KA, Gielen AC, Wu AW, O'Campo P & Faden R (2000) 'Measuring health related quality of life among women living with HIV' *Quality of Life Research* 9 (8): 931-840
- Mekonnen D, Awoke Derbie A & Desalegn E (2015) 'TB/HIV co-infections and associated factors among patients on directly observed treatment short course in North-eastern Ethiopia: A 4 years retrospective study' *BMC Research Notes* 8 (666) 1-6
- Mendelsohn JB, Schilperoord M, Spiegel P & Ross DA (2012) 'Adherence to antiretroviral therapy and treatment outcomes among conflict-affected and forcibly displaced populations: A systematic review' *Conflict & Health* 6(1): 9-9
- Merriam SB, Johnson-Bailey J, Lee M-Y, Kee Y, Ntseane G & Muhamad M (2001) 'Power and positionality: Negotiating insider/outsider status within and across cultures' *International Journal of Lifelong Education* 20(5):406 – 416
- Mertens DM (2005) *Research methods in education and psychology: Integrating diversity with quantitative and qualitative approaches* (2nd edition). California, Thousand Oaks: SAGE
- Miller J, Carr A, Emery S, Law M, Mallal S, Baker D, Smith D, Kaldor J & Cooper DA (2003) HIV lipodystrophy: prevalence, severity and correlates of risk in Australia' *HIV Medicine* 4 (3): 293-301
- Miller AM, Wilbur J, Montgomery A, Chandler PJ & Bezruczko N (2001) 'Measurement properties of the symptom impact inventory' *Journal of Outcome Measures* 4 (4): 763-79
- Mills EJ, Singh S, Nelson BD & Nachega JB (2006) 'The impact of conflict on HIV/AIDS in sub-Saharan Africa' *International Journal of STD & AIDS* 17(11): 713-717
- Ming ZQ, Cheng F, Liu Q, Airawanwat R, Chen YH, Zhu QY, Liu W, Wang Y & Zhang KL (2012) 'A qualitative exploration of the role of antiretroviral therapy on Chinese rural life' *Biomedical & Environmental Sciences* 25 (1): 69- 76
- Mograbi DC, Ferri CP, Sosa AL, Stewart R, Laks J, Brown R & Morris RG (2012) 'Unawareness of memory impairment in dementia: a population-based study' *International Psychogeriatric* 24 (6): 931- 939
- Moore J (2015) Nigerian Military Enter 'Final Stages' of Boko Haram Offensive. *Newsweek*, Available at: <http://europe.newsweek.com/nigerian-military-enter-final-stages-boko-haram-offensive-324384> [Accessed on 15/04/2016]
- Morgan D (1998) Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research* 8 (3) 362-376
- Monjok E, Smesny A, Okokon IB, Mgbere O & Essien EJ (2010) 'Adherence to antiretroviral therapy in Nigeria: An overview of research studies and implications for policy and practice' *HIV/AIDS - Research and Palliative Care* 2: 69–76
- Mrus JM, Leonard AC, Yi MS, Sherman SN, Fultz SL, Justice AC & Tsevat J (2006) 'Health-related quality of life in Veterans and Nonveterans with HIV/AIDS' *Journal of General Internal Medicine* 21: S39–47

- Mueller RO & Hancock GR (2008) Best practices in structural equation modeling. In Osborne JW (ed) *Best practices in quantitative methods*. Thousand Oaks, CA: SAGE Publications Inc
- Mugavero M, Lin H, Allison J, Giordano TP, Willig JH, Raper JL, Wray NP, Cole SR, Schumacher JE, Davies S, Saag MS (2009) 'Racial disparities in HIV virologic failure: Do missed visits matter?' *Journal of Acquired Immune Deficiency Syndrome* 50: 100–108
- Murima O & Fritz K (2009) 'A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings' *Social Science & Medicine* 68(12): 2271–2278
- Murri R, Fantoni M, Del Borgo C, Visona R, Barracco A, Zambelli A, Testa L, Orchi N, Tozzi V, Bosco O & Wu AW (2003) 'Determinants of health-related quality of life in HIV-infected patients' *AIDS Care* 15 (4) 581-590
- Musa AS & Pevalin DJ (2016) 'Development of the Arabic spiritual care in intervention-provision scale' *Journal of Clinical Nursing* 25 (15-16): 2275-2284
- Mutabazi-Mwesigire D, Seeley J, Martin F & Katamba A (2014) 'Perception of quality of life among Ugandan patients living with HIV: a qualitative study' *BMC Public Health* 14 (343) 1-10
- Muturi N & An S (2010) 'HIV/AIDS stigma and religiosity among African American women' *Journal of Health Communication* 15(4): 388-401, DOI: 10.1080/10810731003753125
- Mwesigire DM, Wu AW, Martin F, Katamba A & Seeley J (2015) 'Quality of life in patients treated with first-line antiretroviral therapy containing nevirapine or efavirenz in Uganda: A prospective non-randomized study' *BMC Health Services Research* 15: 292 DOI: 10.1186/s12913-015-0959-0
- Nafada BG, Baba MM, Hylcinta CJ, Tahir A, Tahir B, Talle M & Obi SO (2011) 'Capacity Utilization of University of Maiduguri Teaching Hospital, Nigeria' *Report and Opinion* 3 (8): 35-38
- Narayanasamy A & Andrews A (2000) 'Cultural impact of Islam on the future directions of nurse education' *Nurse Education Today* 20: 57–64
- National Agency for the Control of AIDS (2015) 2014 *Annual report on HIV/AIDS: Health sector response in Nigeria*. NACA, Abuja Available at: <http://naca.gov.ng/2014-annual-report-on-health-sector-hiv-and-aids-in-nigeria/> accessed on 29/04/2017
- National Agency for the Control of AIDS (2015) *Global AIDS response country progress report: Nigeria GARPR 2015*. Abuja, NACA Available at: http://www.unaids.org/sites/default/files/country/documents/NGA_narrative_report_2015.pdf [accessed on 2/05/2017]
- National Agency for the Control of AIDS (2011) *Fact Sheet 2011: Antiretroviral Therapy (ART) in Nigeria*. Abuja, NACA. Available at: <http://naca.gov.ng/content/view/417/lang/en/> [Accessed on 05/01/2013]
- National Agency for the Control of AIDS (2010) *National HIV/AIDS strategic framework 2010-2015*. Abuja, NACA Available at: http://naca.gov.ng/index.php/index.php?option=com_docman&task=cat_view&gid=26&dir=ASC&order=hits&Itemid=99999999&limit=5&limitstart=0 [Accessed on 05/01/2013]
- National Population Commission & ICF Macro (2009) *Nigeria Demographic and Health Survey 2008*. Abuja, NPC and ICF Macro. Available at: <http://www.population.gov.ng/index.php/publications/195-ndhs-2008> [Accessed on 05/01/2013]

- Neha A (2014) 'Does physical activity have an impact on sickness absence? A review' *Sports Medicine* 44 (7): 887-907
- Neuman WL (2011) *Social research methods: Qualitative and quantitative approaches* (7th edition). Boston: Pearson Education Inc
- Neuman WL (2009) *Understanding research*. Boston: Pearson Education Inc
- Nokes KM, Coleman CL, Hamilton MJ, Corless IB, Sefcik E, Kirksey KM, Eller LS, Kempainen J, Dole PJ, Nicholas PK, Reynolds NR, Bunch EH, Holzemer WL, Wantland DJ, Nokes KM, Holzemer WL, Corless IB, Bakken S, Brown MA, Powell-Cope GM, Inouye J & Turner J (2000) 'Health-related quality of life in persons younger and older than 50 who are living with HIV/AIDS' *Research on Aging* 22 (3): 290-310
- Nyblade L, Stangl A, Weiss E & Ashburn K (2009) 'Combating HIV stigma in health care settings: what works?' *Journal of the International AIDS Society* 12: 15 doi:10.1186/1758-2652-12-15
- Nyblade LC, Pande R, Mathur S, MacQuarrie K, Kidd R, Banteyerga H, Kidanu A, Kilonzo G, Mbwambo J & Bond V (2003) *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*. Washington DC, USA, International Center for Research on Women
Available at: <http://www.icrw.org/publications/disentanglinghiv-and-aids-stigma-ethiopia-tanzania-and-zambia> [Accessed on 02/07/16]
- Obi P (2013) 'HIV/AIDS patients discontinue anti-retroviral Drugs' *THISDAY* Available at: <http://www.thisdaylive.com/articles/hiv-aids-patients-discontinue-anti-retroviral-drugs/165767/> [Accessed on 02/12/2013]
- Odili VU, Ikhuronian BI, Usifoh SF & Oparah AC (2011) 'Determinants of quality of life in HIV/AIDS patients' *West African Journal of Pharmacy* 22 (1): 42-48
- Odittah C (2015) Dwindling funds, dearth of personnel impede fight against HIV/AIDS. *The Guardian Nigeria* Available at: <https://guardian.ng/features/dwindling-funds-dearth-of-personnel-impede-fight-against-hiv-aids/> [accessed on 10/06/2017]
- Ogbuji QC & Oke AE (2010) 'Quality of life among persons living with HIV infection in Ibadan Nigeria' *African Journal of Medicine & Medical Sciences* 39 (2): 127-135
- Okeke TC, Anyaehie USB & Ezenyeaku CCK (2012) 'An overview of female genital mutilation in Nigeria' *Annals Medical & Health Science Research* 2(1): 70-73
- Okunoye OC, Asekomeh GE, Otike-Odibi B, Iyagba MA, & Onwuchekwa AC (2014) 'Quality of life of people living with HIV/AIDS in Port Harcourt, Nigeria' *Nigerian Health Journal* 14 (1): 6-12
- Okoror TA, Falade CO, Olorunlana A, Walker EM & Okareh OT (2013) 'Exploring the cultural context of HIV stigma on antiretroviral therapy adherence among people living with HIV/AIDS in Southwest Nigeria' *AIDS Patient Care & STDS* 27: 55-64
- Olisah VO, Baiyewu O & Sheikh TL (2011) 'Depression underdiagnosis and the effects on quality of life in outpatients with HIV at a Nigerian university teaching hospital' *African Journal of AIDS Research* 10 (3): 247-254
- Olley BO & Bolajoko AJ (2008) 'Psychosocial determinants of HIV-related quality of life among HIV-positive military in Nigeria' *International Journal of STD & AIDS* 19 (2): 94-98

- Olsen M, Jensen NK, Tesfaye M & Holm L (2012) 'Conceptual equivalence of WHOQOL-HIV among people living with HIV in Ethiopia' *Quality of Life Research* [Epub ahead of print]
- Olukoya D (2005) *Smite the enemy and he shall flee*. Lagos, Battle Cry publishers
- Olupot-Olupot P1, Katawera A, Cooper C, Small W, Anema A & Mills E (2008) 'Adherence to antiretroviral therapy among a conflict-affected population in North-eastern Uganda: a qualitative study' *AIDS* 22 (14): 1882-1884
- Omer T, Lovering S & Al Shomrani M (2014) 'The lived experience of living with HIV/AIDS in the western region of Saudi Arabia' *Diversity and Equality in Health & Care* 11: 215–223
- Onwuegbuzie AJ & Combs JP (2011) Data analysis in mixed research: A primer. *International Journal of Education* 3 (1) E13
- Onwuegbuzie AJ & Leech NL (2006) Linking research questions to mixed methods data analysis procedures. *The Qualitative Report* 11 (3) 474-498
- Onwuegbuzie AJ & Johnson RB (2006) The validity issue in mixed research. *Research in the Schools* 13 (1) 48-63
- Onwuegbuzie AJ & Teddlie C (2003) A framework for analyzing data in mixed methods research In: Tashakkori A & Teddlie C (eds) (2003) *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: SAGE Publication
- Oshewolo S (2010) 'Galloping poverty in Nigeria: An appraisal of the government's interventionist policies' *Journal of Sustainable Development in Africa* 12 (6): 264-274
- Oturu K (2011) 'Stigma in access to ARVs in Africa: The importance of social connections' *Grounded Theory Review* 10(2): 63-90
- Owen N, Humpel N, Leslie E, Bauman A & Sallis JF (2004) 'Understanding environmental influences on walking: review and research agenda' *American Journal of Preventive Medicine* 27: 67–76
- Oyedepo D (2005) *Walking in the newness of life*. Ota, Dominion Publishers
- Oyeyemi AL, Oyeyemi AY, Jidda ZA & Babagana F (2013) 'Prevalence of physical activity among adults in a metropolitan Nigerian city: A cross-sectional study' *Journal of Epidemiology* 23(3): 169-177
- Oyeyemi AL, Adegoke BO, Sallis JF, Oyeyemi AY, De Bourdeaudhuij I (2012) 'Perceived crime and traffic safety is related to physical activity among adults in Nigeria' *BMC Public Health* 12 (294): 1-10
- O'Brien K, Nixon S, Tynan AM & Glazier RH (2004) 'Effectiveness and safety of aerobic exercise in adults living with HIV/AIDS: Systematic review and meta-analysis of randomized trials' *Medicine & Science in Sports & Exercise* 36: 1659-1666
- O'Cathain A, Murphy E & Nicholl J (2007) 'Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study' *BMC Health Services Research* 7: 85 doi:10.1186/1472-6963-7-85
- O'Leary Z (2004) *The essential guide to doing research*. London: SAGE
- Pacific Regional HIV/AIDS Project Working Group (2009) *HIV and AIDS-Related Stigma and Discrimination: Perspectives of HIV-Positive People in the Pacific*. Pacific Island AIDS Foundation, Rarotonga, Cook Island

- Palfreyman S (2011) 'Patient-reported outcome measures and they are used' *Nursing Older People* 23 (1): 31-36
- Pandya R, Krentz HB, Gill MJ & Power (2005) 'HIV-related neurological syndromes reduce health-related quality of life' *The Canadian Journal of Neurological Sciences* 32: 201-204
- Parameswaran R (2001) 'Feminist media ethnography in India: Exploring power sex and culture in the field' *Qualitative Inquiry* 7(1): 61-103
- Park-Wyllie LY, Strike CS, Antoniou T & Bayoumi AM (2007) 'Adverse quality of life consequences of antiretroviral medications' *AIDS Care* 19 (2): 252-257
- Payne TJ, Andrew M, Butler KR, Wyatt SB, Dubbert PM, Mosley TH (2012) Psychometric evaluation of the interpersonal support evaluation list–Short Form in the ARIC Study Cohort. *SAGE Open* 2 (3) 1-8
- Pedhazur EJ (1997) *Multiple regression in behavioral research: Explanation and prediction* (3rd edition). Wadsworth Publishing Co Inc, New York
- Peltzer K & Ramlagan S (2011) 'Perceived stigma among patients receiving antiretroviral therapy: A prospective study in KwaZulu-Natal South Africa' *AIDS Care* 23 (1): 60-68
- Phaladze NA, Human S, Dlamini SB, Hulela EB, Hadebe IM, Sukati NA, Makoae LN, Seboni NM, Moleko M & Holzemer WL (2005) 'Quality of life and the concept of "living well" with HIV/AIDS in sub-Saharan Africa' *Journal of Nursing Scholarship* 37 (2): 120-126
- Pope C, Ziebland S & Mays N (2000) 'Qualitative research in health care: Analysing qualitative data' *British Medical Journal* 320: 114–116
- Porichis F & Kaufmann DE (2011) 'HIV-specific CD4 T cells and immune control of viral replication' *Current Opinion in HIV & AIDS* 6 (3): 174–180
- Portillo CJ, Mendez MR, Holzemer WL, Corless IB, Nicholas PK, Coleman C, Dole P, Eller LS, Hamilton MJ, Kempainen JK, Kirksey K, Nokes KM, Reynolds N, Wantland DJ, Sefcik EF, Bunch EH & Canaval GE (2005) 'Quality of life of ethnic minority persons living with HIV/AIDS' *Journal of Multicultural Nursing & Health* 11 (1): 31-37
- Power P, Tate HL, McGill SM & Taylor C (2003) 'A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals' *Sexually Transmitted Infections* 79 (2): 137–141
- Premium Times (2017) *Borno records 3800 new cases of HIV in IDPs camps*. Abuja, Premium Times Available at: <http://www.premiumtimesng.com/regional/north-east/228028-borno-records-3800-new-cases-hiv-idps-camps.html> [accessed on 1/05/2017]
- Psaros P, Barinas J, Robbins GK, Bedoya CA, Safren SA, & Park ER (2012) 'Intimacy and sexual decision making: exploring the perspective of HIV positive women over 50' *AIDS Patient Care & STDs* 26 (12): 1-6
- Pulerwitz J, Michaelis A, Weiss E, Brown L & Mahendra V (2010) 'Reducing HIV-related stigma: Lessons learned from Horizons research and programs' *Public Health Report* 125: 272–281
- Ramadhani HO, Thielman NM, Landman KZ, Ndosu EM, Gao F, Kirchherr JL, Shah R, Shao HJ, Morpeth SC, McNeill JD, Shao JF, Bartlett JA & Crump JA (2007) 'Predictors of incomplete adherence, virologic failure and antiretroviral drug resistance among HIV infected adults receiving antiretroviral therapy in Tanzania' *Clinical Infectious Disease* 45: 1492–1498

- Rao D, Chen WT, Pearson CR, Simoni JM, Fredriksen-Goldsen K, Nelson K, Zhao H & Zhang F (2012) 'Social support mediates the relationship between HIV stigma and depression/quality of life among people living with HIV in Beijing China' *International Journal of STD & AIDS* 23 (7): 481-484
- Rapley M (2007) *Quality of life research: a critical introduction* London: SAGE Rogers BA & Carrothers AD (2012) 'Using patient-reported outcome measures to assess health-care quality' *British Journal of Hospital Medicine* 73 (2): 64-65
- Ravens-Sieberer U, Gosch A, Rajmil L, Erhart M, Bruil J, Duer W, Auquier P, Power M, Abel T, Czemy L, Mazur J, Czimbalmas A, Tountas Y, Hagquist C, Kilroe J & Kidscreen Group (2005) 'KIDSCREEN-52 quality-of-life measure for children and adolescents' *Expert Review of Pharmacoeconomics & Outcomes Research* 5 (3): 353-364
- Reyes-Estrada M, Varas-Díaz N & Martínez-Sarson MT (2015) 'Religion and HIV/AIDS Stigma: Considerations for the nursing profession' *New School of Psychology Bulletin* 12(1): 48-55
- Ritchie J & Lewis J (2003) *Qualitative research practice: A guide for social science students and researchers*. London, Sage
- Ritchie J & Spencer L (1994) Qualitative data analysis for applied policy research. In: Bryman A & Burgess RG [eds]. *Analysing Qualitative Data*. London, Routledge
- Rivero-Mendez M, Carmen Portillo C, Solis-Baez SS, Wantland D, & Holzemer WL (2009) 'Symptoms and quality of life for people living with HIV infection in Puerto Rico' *Puerto Rico health Sciences Journal* 28 (1): 54-59
- Rodkjaer L, Sodemann M, Ostergaard L & Lomborg K (2011) 'Disclosure decision: HIV-positive persons coping with disease-related stressors' *Quality of Health Research* 21 (9): 1249-1259
- Rose G (1997) 'Situating knowledge: Positionality, reflexivities and other tactics' *Progress in Human Geography* 21(3): 305- 320
- Rossi R (2010) *Introduction to biostatistics: Applied biostatistics for health sciences*. New York, Wiley
- Rubin HJ & Rubin IS (2005) *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks, CA: Sage.
- Russell S & Seeley J (2010) 'The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Social Science & Medicine* 70: 375-382
- Ryan & Deci (2000) 'Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being' *The American psychologist* 55 (1): 68-78
- Ryu E, West SG & Sousa KH (2009) 'Combining mediation and moderation: Testing relationships between symptom status, functional health and quality of life in HIV patients' *Multivariate Behavioral Research* 44 (2): 213-232
- Saban KL, Penckofer SM, Androwich I & Bryant FB (2007) Health-related quality of life of patients following selected types of lumbar spinal surgery: A pilot study' *Health & Quality of Life Outcomes* 5: 71

- Sabin LL, Desilva MB, Hamer DH, Keyi X, Yue Y, Wen F, Tao L, Heggenhougen HK, Seton L, Wilson IB & Gill CJ (2008) 'Barriers to adherence to antiretroviral medications among patients living with HIV in southern China: a qualitative study' *AIDS Care* 20 (10): 1242-1250
- Safren SA, Hendriksen ES, Smeaton L, Celentano DD, Hosseinipour MC, Barnett R, Guanira J, Flanigan T, Kumarasamy N, Klingman K & Campbell T (2012) 'Quality of life among individuals with HIV starting antiretroviral therapy in diverse resource-limited areas of the world' *AIDS & Behavior* 16 (2): 266-277
- Scanlon ML & Vreeman RC (2013) 'Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings' *HIV AIDS (Auckland)* 5: 1-17
- Schipper H, Clinch J & Olweny CLM (1996) Quality of life studies: definitions and conceptual issues. In: Spilker B, (ed). *Quality of Life and Pharmacoeconomics in Clinical Trials*. 2nd ed. Philadelphia: Lippincott-Raven Publishers; 11-23
- Seeley J & Russell S (2010) 'Social rebirth and transformation? Rebuilding social lives after ART in rural Uganda' *AIDS care* 22 (Suppl 1): 41-49
- Segerstrom & Miller (2004) 'Psychological stress and the human immune system: A meta-analytic study of 30 years of inquiry' *Psychological Bulletin* 130(4): 601-630
- Sethi AK, Celentano DD, Gange SJ, Moore RD & Gallant JE (2003) 'Association between adherence to antiretroviral therapy and HIV resistance' *Clinical Infectious Disease* 37: 1112-1118
- Shan D, Ge Z, Ming S, Wang L, Sante M, He W, Zhou J, Liu S & Wang L (2011) 'Quality of life and related factors among HIV-positive spouses from serodiscordant couples under antiretroviral therapy in Henan Province, China' *PLoS One* 6 (6): e21839
- Sibbrit DW, Byles JE & Regan C (2007) 'Factors associated with decline in physical functional health in a cohort of older women' *Age Ageing* 36 (4): 382-388
- Siddiqui TR, Ghazal S, Bibi S, Ahmed W & Sajjad SF (2016) 'Use of the Health Belief Model for the assessment of public knowledge and household preventive practices in Karachi, Pakistan, a Dengue-Endemic City' *PLOS Neglected Tropical Diseases* 10(11): e0005129. doi: 10.1371/journal.pntd.0005129
- Simoni, J, Martone G & Kerwin F (2002) 'Spirituality and psychological adaptation among women with HIV/AIDS: Implications for counselling' *Journal of Counselling Psychology* 49(2): 139-147
- Skevington SM, Lotfy M, & O'Connell KA (2004) 'The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial, a report from the WHOQOL Group' *Quality of Life Research* 13: 299-310
- Smith J & Firth J (2011) 'Qualitative data analysis: application of the framework approach' *Nurse Researcher* 18 (2): 52-62
- Smith SJ (1993) 'Bounding the borders: Claiming space and making place in rural Scotland' *Transactions of the Institute of British Geographers* 18(3): 291-308
- Soghoian DZ, Jessen H, Flanders M, Sierra-Davidson K, Cutler S, Pertel S, Ranasinghe S, Lindqvist M, Davis I, Lane K, Rychert J, Rosenberg ES, Piechocka-Trocha A, Brass AL, Brenchley JM, Walker BD & Streeck H (2012) 'HIV-Specific cytolytic CD4 T cell responses during acute HIV infection predict disease outcome' *Science Translational Medicine* 4 (123): 1-10

- Sosulski MR & Lawrence C (2008) 'Mixing methods for full-Strength results: Two welfare studies' *Journal of Mixed Methods Research* 2 (2): 121-148 doi: 10.1177/1558689807312375
- Sousa KH & Kwok OM (2006) 'Putting Wilson and Cleary to the test: analysis of a HRQOL conceptual model using structural equation modelling' *Quality of Life Research* 15 (4): 725-737
- Sousa KH & Chen FF (2002) 'A theoretical approach to measuring quality of life' *Journal of Nursing Measurement* 10 (1): 47-58
- Sousa KH, Holzemer WL, Henry SB & Slaughter R (1999) 'Dimensions of health-related quality of life in persons living with HIV disease' *Journal of Advanced Nursing* 29 (1): 178-187
- Sowell L, Moneyham L, Hennessy M, Guillory J, Demi A & Seals B (2000) 'Spiritual activities as a resistance: Resource for women with human immunodeficiency virus' *Nursing Research* 49(2): 73-82
- Spencer L, Ritchie J, Lewis J & Dillon L (2003) *Quality in qualitative evaluation: A framework for assessing research evidence*. Government Chief Social Researcher's Office, London: Cabinet Office
- Spiegel PB, Bennedsen AR, Claass J, Bruns L, Patterson N, Yiweza D & Schilperoord M (2007) 'Prevalence of HIV infection in conflict-affected and displaced people in seven sub-Saharan African countries: a systematic review' *The Lancet* 369 (9580): 2187-2195
- Spiegel PB (2004) 'HIV/AIDS among conflict-affected and displaced populations: dispelling myths and taking action' *Disasters* 28 (3): 322-339
- Sremac S (2010) 'Converting into a new reality: Social constructionism, practical theology and conversion' *Nova Pristnost* 8 1, 7-27
- Srivastava A & Thomson SB (2009) 'Framework analysis: A qualitative methodology for applied policy research. *Journal of Administration & Governance* 4 (2): 72-79
- Ssali SN, Atuyambe L, Tumwine C, Segujja E, Nekesa N, Nannungi A, Ryan G & Wagner G (2010) 'Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: An exploratory study' *AIDS Patient Care & STDs* 24 (10): 675-681
- Stangl AL, Wamai N, Mermin J, Awor AC & Bunnell RE (2007) 'Trends and predictors of quality of life among HIV-infected adults taking highly active antiretroviral therapy in rural Uganda' *AIDS Care* 19 (5): 626-636
- Stineman MG, Ross RN & Maislin G (2005) 'Functional status measures for integrating medical and social care' *International Journal of Integrated Care* 5, 1-10
- Strathdee SA, O'Shaughnessy MV, Montaner JS, & Schechter MT (1996) 'A decade of research on the natural history of HIV infection: Part 1. Markers Clinical & Investigative Medicine' *Medecine Clinique et Experimentale* 19 (2): 111-120
- Szabo G & Mandrekar PA (2009) 'Recent perspective on alcohol, immunity, and host defense' *Alcoholism: Clinical and Experimental Research* 33: 220-232
- Szaflarski M (2013) 'Spirituality and religion among HIV-infected individuals' *Current HIV/AIDS Reports* 10 (4) 324-332
- Tabachnick BG & Fidell LS (2007) *Experimental design using ANOVA*. Belmont, CA: Buxbury/Thomson/Books/Cole

- Tashakkori A & Teddlie C (eds) (2003) *Handbook on mixed methods in the behavioral and social sciences*. Thousand Oaks, CA: SAGE
- Tashakkori A & Teddlie C (1998) *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: SAGE
- Templeton GF (2011) 'A two-step approach for transforming continuous variables to normal: Implications and recommendations for IS research' *Communications of the Association for Information Systems* 28 (4) 41-58
- Testa MA & Lenderking WR (1999) 'The impact of AIDS-associated wasting on quality of life: Qualitative issues of measurement and evaluation' *The Journal of Nutrition* 129: 282S–289S
- Tifratene K, Robert P, Metelkina A, Pradier C & Dartigues JF (2015) 'Progression of mild cognitive impairment to dementia due to AD in clinical settings' *Neurology* 85 (4): 331-338
- Thapa R, Amatya A, Pahari DP, Bam K & Newman MS (2015) 'Nutritional status and its association with quality of life among people living with HIV attending public anti-retroviral therapy sites of Kathmandu Valley, Nepal' *AIDS Research and Therapy* 12:14 DOI 10.1186/s12981-015-0056-9
- The Guardian (2015) 'Nigerian army frees hundreds more women and girls from Boko Haram'. The Guardian online news. Available at: <https://www.theguardian.com/world/2015/may/02/nigerian-women-girls-boko-haram-rebel> [Accessed on 28/07/2016]
- The Survey System (2012) *Sample Size Formulas for our Sample Size Calculator* Available at <http://www.surveysystem.com/sample-size-formula.htm> [Accessed on 20/04/2014]
- The WHOQOL HIV Group (2004) 'WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: results from the field test' *AIDS Care* 16 (7): 882-889
- The WHOQOL Group (1998) 'Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment' *Psychological Medicine* 28 (3): 551-558
- The World Bank (2016) *World Bank Scales up Support for Nigeria's North-East Region*. Abuja, Nigeria Available at: <http://www.worldbank.org/en/news/press-release/2016/06/07/world-bank-scales-up-support-for-nigerias-north-east-region> [Accessed on 15/08/2016]
- Thomas BE, Rehman F, Suryanarayanan D, Josephine K, Dilip M, Dorairaj VS & Swaminathan S (2005) 'How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai South India' *AIDS Care* 17 (7): 795-801
- Tukey JW (1977) *Exploratory data analysis*. Reading MA: Addison-Wesley
- Tuli F (2010) 'The basis of distinction between qualitative and quantitative research in social science: Reflection on ontological, epistemological and methodological perspectives' *Ethiopian Journal of Education & Science* 6 (1): 97-107
- Treloar C, Champness S, Simpson PL & Higginbotham (2000) 'Critical appraisal checklist for qualitative research' *The Indian Journal of Paediatrics* 67(5) 347-351
- Tsai YF, Rivero-Mendez M & Canaval GE (2011) 'Age-related effects on symptom status and health-related quality of life in persons with HIV/AIDS' *Applied Nursing Research* 24 (1): 10–16

Ulvik B, Nygård O, Hanestad BR, Wentzel-Larsen T & Wahl AK (2008) 'Associations between disease severity, coping and dimensions of health-related quality of life in patients admitted for elective coronary angiography – A cross sectional study' *Health & Quality of Life Outcomes* 6: 38

United Nation Children Education Fund (2010) *At a glance: Nigeria. Abuja*, UNICEF Available at: http://www.unicef.org/infobycountry/nigeria_statistics.html [Accessed on 05/01/2013]

United Nations Development Programme (2011) *Sustainability and equity: A better future for all (Human Development Report 2011)*. New York, UNDP Available at: http://hdr.undp.org/en/media/HDR_2011_EN_Complete.pdf [Accessed on 06/01/2013]

United Nations Development Programme (2009) *Nigeria Human Development Report 2008 – 2009: Achieving growth with equity*. Abuja, UNDP Nigeria Available at: http://hdr.undp.org/en/reports/national/africa/nigeria/NHDR_Nigeria_2008-2009.pdf [Accessed on 05/01/2013]

United Nations High Commissioner for Refugees (2007) *Antiretroviral medication policy for refugees*. Geneva, UNHCR Available at http://data.unaids.org/pub/Report/2007/20070326_unhcr_art_en.pdf [Accessed on 25-12-2015]

United Nations Population Fund (2010) *Adolescents population: Selected socio-demographic variables*. Abuja, UNFPA Available at: <http://nigeria.unfpa.org/pdf/adolescents2010.pdf> [Accessed on 05/01/2013]

United Nations Programme on HIV and AIDS (2016) *On the fast-track to end AIDS: 2016-2021 strategy*. Geneva, Switzerland, UNAIDS Available at: http://www.unaids.org/sites/default/files/media_asset/20151027_UNAIDS_PCB37_15_18_EN_rev1.pdf [Accessed on 17/11/2016]

United Nations Programme on HIV and AIDS (2015) *Nigeria: HIV and AIDS estimates (2015)*. Abuja, UNAIDS Available at: <http://www.unaids.org/en/regionscountries/countries/nigeria> [accessed on 2/05/2017]

United Nations Programme on HIV and AIDS (2004) *Nigeria Epidemiological fact sheets on HIV/AIDS and sexually transmitted infection 2004 update*. Abuja, UNAIDS Available at: http://data.unaids.org/publications/fact-sheets01/nigeria_en.pdf [accessed on 4/05/2017]

Vallerand AH, Breckenridge DM & Hodgson N (1998) Theories and conceptual models to guide quality of life research. In: King CR & Hinds PS (eds) *Quality of life: Theory, research and practice* Boston: Jones & Bartlett

Vancampfort D, Koyanagi A, Ward PB, Rosenbaum S, Schuch FB, Mugisha J, Richards J, Firth J & Stubbs B (2017) 'Chronic physical conditions, multimorbidity and physical activity across 46 low- and middle-income countries' *International Journal of Behavioral Nutrition & Physical Activity* (2017) 14:6 DOI 10.1186/s12966-017-0463-5

Vanderbeck RM (2005) 'Masculinities and fieldwork: widening the discussion' *Sex, Place & Culture* 12(4): 387-402

Vanguard Nigeria (2017) *Breaking News: Agency provides HIV/AIDS support services to 100863 persons in Borno*. Lagos, Vanguard Available at: <http://www.vanguardngr.com/2017/04/agency-provides-hiv-aids-support-services-100863-persons-borno/> [accessed on 1/05/2017]

Vanhook PM (2007) 'Cost-Utility Analysis: A method of quantifying the value of registered nurses' *The Online Journal of Issues in Nursing* 12 (3) Manuscript 5. Available at:

<http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/T/ableofContents/Volume122007/No3Sept07/CostUtilityAnalysis.html> [Accessed on 24/09/2013]

Veenhoven R (2000) 'The four qualities of life: Ordering concepts and measures of the good life' *Journal of Happiness Studies* 1:1-39

Vidrine DJ Amick BC Gritz ER & Arduino RC (2005) 'Assessing a conceptual framework of health-related quality of life in a HIV/AIDS population' *Quality of Life Research* 14 (4): 923-933

Wagner G, Ryan G, Huynh A, Kityo C & Mugenyi P (2011) 'A qualitative exploration of the impact of HIV and ART on social disruption and household continuity in Uganda' *African Journal of AIDS Research* 10 (1): 37-42

Ward DJ, Furber C, Tierney S & Swallow V (2013) 'Using Framework Analysis in nursing research: a worked example' *Journal of Advance Nursing* 69 (11): 2423-2431

Ware J (1997) *SF-36 Health Survey: Manual and Interpretation Guide*. Nimrod Press

Ware J, Kosinski M, Turner-Bowker D & Gandek B (2002) *How to score Version Two of the SF-36 Health Survey (with a supplement documenting Version 1)*. Lincoln: RI Quality Metric Inc

Watkins K & Connell CM (2004) 'Measurement of health-related QOL in diabetes mellitus' *Pharmacoeconomics* 22(17): 1109-1126

Watts CH, Foss AM, Hossain M, Zimmerman C, von Simson R & Klot J (2010) 'Sexual violence and conflict in Africa: prevalence and potential impact on HIV incidence' *Sexually Transmitted Infections* Suppl 3 (3) 93-99

Wieseler B & McGauran N (2011) 'Reporting a Systematic Review' *Chest* 137 (5): 1240-1246

Wilson IB & Cleary PD (1997) 'Clinical predictors of declines in physical functioning in persons with AIDS: Results of a longitudinal study' *Journal of Acquired Immune Deficiency Syndrome & Human Retrovirology* 16 (5): 343-349

Wilson IB & Cleary PD (1996) 'Clinical predictors of functioning in persons with acquired immunodeficiency syndrome' *Medical Care* 34 (6): 610-623

Wilson IB & Cleary PD (1995) 'Linking clinical variables with health-related quality of life: A conceptual model of patient outcomes' *Journal of the American Medical Association* 273 (1): 59-65

Wood GG & Tully CT (2005) *The structural approach to direct practice in social work: A Social constructionist perspective* (3rd Edition). New York: Columbia University Press

World Bank (2017) *Overview of Nigeria*. Abuja, Nigeria Available at: <http://www.worldbank.org/en/country/nigeria/overview> accessed on 28/04/2017

World Health Organisation (2013) *Global AIDS response progress reporting 2013: Construction of Core Indicators for monitoring the 2011 UN Political Declaration on HIV/AIDS*. Geneva: WHO Available at: http://apps.who.int/iris/bitstream/10665/78126/1/9789292530068_eng.pdf?ua=1 [Accessed on 05/11/2013]

World Health Organisation (2011a) *Global Health Sector Strategy on HIV/AIDS 2011-2015* Geneva: WHO Available at: http://www.who.int/hiv/pub/progress_report2011/en/index.html [Accessed on 05/01/2013]

World Health Organisation (2011b) *Global HIV/AIDS response epidemic update and health sector progress towards Universal Access: Progress report 2011* Geneva: WHO Available at: http://whqlibdoc.who.int/publications/2010/9789241500395_eng.pdf [Accessed on 05/01/2013]

World Health Organisation/Federal Ministry of Health (2010) *National guidelines for HIV and AIDS treatment and care in adolescents and adults*. Abuja: WHO/FMoH 2010 Available at: http://www.who.int/hiv/pub/guidelines/nigeria_art.pdf [Accessed on 26/11/2013]

World Health Organisation (2006) *Antiretroviral drugs in emergencies: neglected but feasible. Consensus statement*. WHO, Geneva Available at: www.who.int/hac/techguidance/pht/HIV_AIDS_101106_arvemergencies.pdf [Accessed on 25-12-2015]

World Health Organisation (2003) *Nutrient requirements for people living with HIV/ AIDS: report of a technical consultation*. Geneva, WHO. Available at: <http://www.who.int/nutrition/publications/hivaids/9241591196/en/> [Accessed on 03/06/2013]

Wu AW, Rubin HR, Mathews WC, Ware JE Jr, Brysk LT, Hardy WD, Bozzette SA, Spector SA, Richman DD (1991) 'A health status questionnaire using 30 items from the Medical Outcomes Study. Preliminary validation in persons with early HIV infection' *Medical Care* 29 (8): 786-798

Yardley L (2000) 'Dilemmas in qualitative health research' *Psychology & Health* 15(2): 215-228

Zigmond AS & Snaith RP (1983) 'The hospital anxiety and depression scale' *Acta psychiatrica Scandinavica* 67 (6): 361-370

Zubaran C, Medeiros G, Foresti K, May W, Michelim L, Madi JM & UCS-UNESCO Research Group (2014) 'Quality of life and adherence to antiretroviral therapy in Southern Brazil' *AIDS Care* 26 (5): 619-625

Zavella P (1996) Feminist insider dilemmas: Constructing ethnic identity with Chicana informants In: Wolf DL (Ed) *Feminist dilemmas in field work*. Boulder CO Westview Press

Appendix I

I. Combination of Keywords to search for studies from PubMed database (1996-2016)

Search number	Keywords combination	Output	Relevant for abstract examination	Relevant for complete full-text examination	Final result for inclusion
1	"Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL	200982			
2	"Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS"	245537			
3	"Wilson and Cleary model" OR "conceptual framework" OR "conceptual model"	1681734	0	0	0
4	1 AND 2	3742			
5	1 AND 2 AND 3	380	9	9	7
6	1 AND 2 AND 3 and Nigeria	1	0	0	0
7	1 AND 2 AND Nigeria	58	9	7	7
8	1 AND 2 AND "Qualitative research" OR "qualitative study"	133	7	7	7
9	1 AND 2 AND "Qualitative research" OR "qualitative study" AND Nigeria	2	1	1	1

II. Combination of Keywords to search for studies from Medline database (1996-2016)

Search number	Keywords combination	Output	Relevant for abstract examination	Relevant for complete full-text examination	Final result for inclusion
1	"Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL	207426			
2	"Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS"	243890			
3	"Wilson and Cleary model" OR "conceptual framework" OR "conceptual model"	1316251	0	0	0
4	1 AND 2	4085			
5	1 AND 2 AND 3	613	7	6	6
6	1 AND 2 AND 3 and Nigeria	4	0	0	0
7	1 AND 2 AND Nigeria	64	8	6	6
8	1 AND 2 AND "Qualitative research" OR "qualitative study"	132	8	8	8
9	1 AND 2 AND "Qualitative research" OR "qualitative study" AND Nigeria	2	1	1	1

III. Combination of Keywords to search for studies from CINAHL (1996-2016)

Search number	Keywords combination	Output	Relevant for abstract examination	Relevant for complete full-text examination	Final result for inclusion
1	"Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL	105123			
2	"Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS"	79210			
3	"Wilson and Cleary model" OR "conceptual framework" OR "conceptual model"	379	4	4	4
4	1 AND 2	1945			
5	1 AND 2 AND 3	3	3	3	3
6	1 AND 2 AND 3 and Nigeria	0	0	0	0
7	1 AND 2 AND Nigeria	17	3	3	3
8	1 AND 2 AND "Qualitative research" OR "qualitative study"	32	3	3	3
9	1 AND 2 AND "Qualitative research" OR "qualitative study" AND Nigeria	0	0	0	0

IV. Combination of Keywords to search for studies from Wed of Science (1996-2016)

Search number	Keywords combination	Output	Relevant for abstract examination	Relevant for complete full-text examination	Final result for inclusion
1	"Quality of life" OR "Health related quality of life" OR QOL OR HRQOL OR HQOL	258124			
2	"Human immunodeficiency virus" OR "HIV infection" OR HIV OR "HIV/AIDS"	2791211			
3	"Wilson and Cleary" OR "conceptual framework" OR "conceptual model"	6,102,094			
4	1 AND 2	4291			
5	1 AND 2 AND 3	844	8	8	8
6	1 AND 2 AND 3 AND Nigeria	0	0	0	0
7	1 AND 2 AND Nigeria	29	3	3	3
8	1 AND 2 AND "Qualitative research" OR "qualitative study"	181	8	7	7
9	1 AND 2 AND "Qualitative research" OR "qualitative study" AND Nigeria	3	1	1	1

Appendix II A



15 September 2014

MR ISMAIL SAIDU
16 WESTCHESTER DRIVE
HENDON
LONDON
NW4 1RD

Dear Ismail,

Re: Ethical Approval Application (Ref 13022a)

Further to your application for an amendment to your ethical approval form, please find enclosed a copy of your amendment request form which has now been approved by Dr Wayne Wilson on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Human Sciences

cc. Sarah Manning-Press, REO
Gill Green, Supervisor

Appendix IIB

University of Maiduguri Teaching Hospital Ethical Approval Letter

UNIVERSITY OF MAIDUGURI TEACHING HOSPITAL

Chairman Board of Management
Prof. Sadiq S. Wali, MSc
FRCP (London); FWACP; FMCP; DTPH
Ag. Director of Administration
Babagana Mohammed BA, MPA



Chief Medical Director
Prof. A. Tahir, FWACS, FMCR, FAMS
Chairman Medical Advisory Committee
Dr. M. B. Tahir, FWACS

P.M.B. 1414 Bama Road, Maiduguri, Nigeria
E-mail: cmd_umth@yahoo.com

11th February, 2015.

Ismaila Adamu Saidu,
Department of Physiotherapy,
University of Maiduguri Teaching Hospital,

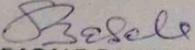
Sir,

**RE: REQUEST FOR ETHICAL CLEARANCE/APPROVAL TITLED:
ASSESSING HEALTH –RELATED QUALITY OF LIFE OF PERSONS LIVING WITH
HIV IN BORNO, NIGERIA: A MIXED METHODS RESEARCH.**

Yours on the above subject dated 4th February, 2015 refers.

That after careful review of your proposal and preformed by the Research and Ethical Committee, approval is hereby given. However, feedback of the outcome of the study is hereby mandated.

Good luck.


BABALE GARBA NAFADA
Secretary, Research & Ethical Committee

All Correspondence to the Chief Medical Director

Appendix III



Participant's Information Sheet for the Quantitative Research

Title of Project: **Assessing health-related quality of life of people infected with HIV/AIDS in Maiduguri, Nigeria**

Thank you for considering to participate in this research project to assess the **health-related quality of life of people infected with HIV/AIDS in Maiduguri, Nigeria**. The purpose of the study is to examine the impact of HIV on the quality of life people infected with HIV and explore the in-depth understanding and meaning of quality of life of HIV infected persons in Nigeria. The information that you provide will contribute to my PhD Research Project taking place at The University of Essex, UK. The project will also help to improve services for HIV care in Nigeria. The project has received ethical approval from the University of Essex and University of Maiduguri Teaching Hospital Ethics Committee, Maiduguri, Nigeria and is being supervised by Prof Gill Green and Dr Sheila Black of the University of Essex, UK. Your participation is entirely voluntary and will have no impact on the treatment or care you receive.

What will happen:

You will be asked to tick an appropriate answer to the attached questionnaire as it applies to you.

Participants' rights:

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed. In addition, you have the right to omit or refuse to answer or respond to any question that is asked of you if you so wish.

You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins. However, if you choose not to take part in the study this will in no way affect the HIV treatment you are currently receiving.

Benefits and risks:

There are no known benefits or risks for you in this study. However, the results may help to improve HIV care services.

Cost, reimbursement and compensation:

Your participation in this study is voluntary.

Confidentiality/ anonymity:

The data collected does not contain any personal information about you such as name and address except sex, marital status and age. The data obtained will be stored privately by password protecting the research database. The data will only be shared among the principal investigators (the student and supervisors). Hard copies of materials (returned questionnaires) will be stored in my locked cabinet.

For further information

Please contact: **Ismaila Saidu** – mobile phone: +447586592526 (UK number) and +2348148060361 (Nigerian number) email: iasaid@essex.ac.uk – who will be glad to answer your questions about this study at anytime

Appendix IV



CONSENT FORM FOR THE QUANTITATIVE RESEARCH

Title of Project: **Assessing health-related quality of people infected with HIV/AIDS in Maiduguri, Nigeria**

Name of Researcher: **Ismaila A Saidu**

PLEASE INITIAL ALL BOXES

- 1. I confirm that I have read and understand the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- 3. I understand that anonymised relevant sections of my data collected during the study may be looked at by individuals from the University of Essex and I give permission for these individuals to have access to my anonymised data.
- 4. I agree to take part in the above study.

Name of Participant:

Signature: Date:

Name of Person taking consent:

Signature: Date:.....

Appendix V



Sociodemographic data form

1. Age: _____years

2. Sex: Male male

3. Marital status: Married Single divorce Widow/widower

4. Place of resident: Town/city Village

5. Education: Primary Secondary College/University

6. Type of job: _____

7. Smoking: Never Occasionally Regularly

8. Alcohol intake: Never Occasionally Regularly

9. Drug use: Never Occasionally Regularly

Kindly provide your phone if wish to participate in the interview session.....

Appendix VI



Biological function/clinical information data from Participant's case-note

1. Recent CD4+ count: _____

2. Time since HIV diagnosis: _____

3. Comorbidity (ies): Hepatitis Hypertension Diabetes
 Stroke Heart disease Tuberculosis
 others _____

Appendix VII

Protocol number	_ _ _ _	Center number	_ _ _ _	Date of subject visit	_ _ - _ _ - _ _	Subject number	_ _ _ _
Mode of completion:		<input type="checkbox"/> Self-completed		<input type="checkbox"/> Face to face interview			

PROQOL-HIV Quality of Life HIV Questionnaire

Instructions

This questionnaire asks you how HIV and its treatment have affected your health and your life.

For each of the following questions, please check the box best suited to your personal situation. When you don't know how to reply, give what you consider to be the most appropriate answer.

We want you to think about your life **during the last two weeks**.

Make sure you answer **each question** by checking a single box for each line.

	Very good	Good	Fair	Poor	Very poor
1. During the last two weeks, my overall health (both HIV and non-HIV related) has been	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last two weeks, because I am HIV positive...	Never	Rarely	Some-times	Often	Always
2. I have felt tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I have had difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I have had difficulty concentrating or paying attention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I have had problems with my memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I have had difficulty with daily activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have had difficulty with strenuous physical activities such as carrying heavy objects, running, or walking a long distance, climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I have been bothered by digestive problems (stomach ache, bloating, diarrhoea, nausea or vomiting)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I have been bothered by pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have had a poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last two weeks, because I am HIV positive...	Never	Rarely	Some-times	Often	Always
11. I have been bothered by a change in weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I have been bothered by skin problems (dry skin, itching, rash)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I have been bothered by the changes in my body shape (sunken cheeks, thinner legs or arms, smaller buttocks, larger chest or breasts, fat belly, fat at the back of the neck)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I have been unhappy with my physical appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last two weeks, because I am HIV positive...	Never	Rarely	Some-times	Often	Always
15. I have avoided going out with my friends or my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I have felt restricted in my relationships with my family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I have had difficulties with my love life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My sexual desire has diminished	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I have felt restricted in my sexual activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I have been afraid of disclosing that I am HIV positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I have been afraid of infecting others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last two weeks, because I am HIV positive...	Never	Rarely	Some-times	Often	Always
22. I have been sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I have been anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have been more irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I have been depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. HIV was on my mind	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I have worried about the results of my follow-up tests such as viral load or T cells	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I have been afraid that my disease will get worse one day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I have been afraid of catching infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the last two weeks, because I am HIV positive...	Never	Rarely	Some-times	Often	Always
30. My spiritual or religious beliefs have helped me to live with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I have been satisfied with the health care I received	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I have had financial difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. The thought that it will be difficult for me to have a child has worried me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you **are taking HIV medicine**, please **continue** to the end

If you are **not taking any HIV medicine**, please **stop** to fill the questionnaire

During the last two weeks, because I am taking HIV medicine...	Never	Rarely	Some-times	Often	Always
34. Having to take my HIV medicine everyday has bothered me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I have been satisfied with my HIV medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. I have been bothered by the side effects of my HIV medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. The size of the pills has bothered me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. The number of pills per day has bothered me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I have been bothered by the number of times I have had to take my HIV medicine each day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I have had to hide in order to take my HIV medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I have felt like changing my HIV medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Because of my HIV medicine, I have had difficulty going out with my friends or family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I have forgotten to take my HIV medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Before returning this questionnaire,
please make sure you have answered **all** the questions

Thank you

Appendix II B

Hausa language translated copy of PROQOL-HIV questionnaire

SUMA.....Shekaru..... Lamba.....

PROQOL-HIV

Tambayoyi akan sannin rayuwa mai ingancin

Umurni

Wannan tambayoyi tambaye akan yadda rayuwa da ciwon kanjamo ke shaffan lafiya da rayuwa yau da kullum.

Zabi amsan tambayoyin yada ya dace da kai/ki da sa miki.

S/No		Mai kyau da mutukan gaske	Mai kyau	Da dan dama	Ba dadi	Ba dadi so sai
1	Cikin mako biyu da suka wuce, lafiya na gabaki ɗaya (na ciwon kanjamo da wanda bana kanjamoba) ya kasance					
	Cikin mako biyu da suka wuce, sabo da na kasance mai fama da cutar kanjamo	Babu sam	Ba ko wane lokaci ba	Lokaci lokaci	Sau da yawa	Ko da yausha
2	Nakan ji gajiya					
3	Nakan samun matsalar yin barci					
4	Nakan sami matsalar maida hankali akan abubuwa					
5	Nakan sami matsaloli tare da na tuna abubuwa					
6	Nakan sami matsalar gudanar da ayyukan yau da kullum					
7	Nakan samai matsalar gudanar a ayyuka mai sauri kamar daukar abi mai nauyi, guduwa, ko tafiya wuri mai nisa a kafa, hawar matattakala mai yawa					
8	Nakan fama da matsalar ciki (kamar mudar ciki, kugi ciki, gudawa, tashin zuciya ko amai)					
9	Nakan fama da ciwon jiki					
10	Nakan fama da rashin dadin baki da cima					
11	Nakan fama da matsalar canjin nauyin jiki					
12	Nakan fama da matsaloli fata (bushewan fata, kaikayi, kuraje)					
13	Na kasance mai rashin jin farin ciki dame da kasancewar sifar jikina					
14	Ina mutukar damuwa da canje-canje a siffar jikina siffar (ramar kumatunta, tsirarun kafafu ko hannaye, motsassun duwawu, manyar kirji ko nono, ko dantse a bayan wuya)					
15	Ina kauracewa wajen fita yawo shakatawa tare da abokaina ko 'yan'uwa					
16	Inaji Ina kuntace nayi mu'amula ko dangantaka tare da 'yan'uwana ko abokai					
17	Ina samun matsaloli wajen gudanar rauwar soyayya a gareni					
18	Ina jin raguwar sha'awar jima'i					
19	Ina jin kuntatawa na sha'awa ko jima'i					
20	Na kasance mejin tsoro wajen bayyana cewa ni ina fama cutar kanjamo					
21	Na kasance mejin tsoro bawa wani cutar kanjamo					
22	Na kasance zama a cikin bakin ciki					
23	Na kasance a cikin fargaba da tashin hankali					
24	Na kasance mai yawan samun bacin rai					
25	Na kasance merashinin menene kasancewar rayuwa					
26	Na kasance mai tunanin ciwon kanjamo a rai na					
27	Ina mutukar damuwa game da amsar gwaje-gwajena na asibiti na sani garkuwan jikina (CD4 count, viral load)					
28	Ina mutukar damuwa kasancewa cutana na kanjamo zai munana nan gaba					
29	Na kasance mejin tsoro na kamawa cututtuka					
30	Ruhanena ko addini sun taimaka mini yin rayuwa ta ciwon kanjamo na					
31	Ina mutukar gamsuwa da kiwon lafiya da ake bani					
32	Ina samu matsaloli tattalin aziki ko kudi					
33	Tsammani kasancewa zai wuya a gare ni in aihu nangaba a rayuwana na mutukar damuna					

PROQOL-HIV...cigaba

1. In kana/kina shan magani, cigaba da amsa tambayoyi da suka gabata zuwa karshe						
2. In baka/baki shan magani, bar amsa suran tambayoyin wanna						
Cikin mako biyu da suka wuce, sabo da na kasance mai fama da cutar kanjamo		Babu sam	Ba ko wane lokaci ba	Lokaci lokaci	Sau da yawa	Ko da yausha
34	Ina mutukar damuwa na shan maganina na ciwon kanjamo kowane rana					
35	Ina mutukar gamsuwa da magungunan cutar kanjamo na					
36	Ina mutukar damuwa da illolin magungunan cutar kanjamo na					
37	Ina mutukar damuwa da girmar kwayoyin da nake sha					
38	Ina mutukar damuwa da yawan kwayoyi da zansa a rana					
39	Ina samun matsaloli na yawan lokatai a rana na kasance na shan maganina na ciwon kanjamo					
40	Nakan boye 6 o domin insha maganina na ciwon kanjamo					
41	Na ji kamar in canza maganina na ciwon kanjamo					
42	Ina samun matsaloli mu'amula ko wajen fita yawon shakatawa tare da 'yan'uwa da abokai, saboda shan maganina na ciwon kanjamo					
43	Na manta shan maganina na ciwon kanjamo					

Kafin ya dawo wannan tambayoyi, don Allah a tabbata ka amsa duk tambayoyin

Appendix VIII A

Reference Number _____

Interpersonal Support Evaluation List-Short Form

Instructions: This questionnaire is made up of a list of statements which may or may not be true about you. For each item, please indicate whether you think that the statement is applicable to you by marking **X** in the appropriate box. That is, either **Definitely False**, **Probably False**, **Probably True** or **Definitely True**.

S/No	Questions	Definitely False - 0	Probably False - 1	Probably True - 2	Definitely True - 3
1	There is at least one person I know whose advice I really trust.				
2	There is really no one I can trust to give me good financial advice				
3	There is a really no one who can give me objective feedback about how I'm handling problems.				
4	When I need suggestions for how to deal with a personal problem, I know someone I can turn to.				
5	I don't often get invited to do things with others.				
6	When I feel lonely, there are several people I could call and talk to.				
7	I regularly meet or talk with members of my family or Friends.				
8	I feel that I'm on the fringe of my circle of friends.				
9	If I had to go out of town for a few weeks, someone I know would look after my house.				
10	If I were sick and needed someone to drive me to the doctor, I would have trouble finding someone.				
11	If I were sick, there would be almost no one I could find to help me with my daily chores.				
12	If I had to mail an important letter at the post office by 5:00 and couldn't make it, there is someone who could do it for me.				
13	Most of my friends are more successful at making changes in their lives than I am.				
14	Most of my friends are more interesting than I am.				
15	I am more satisfied with my life than are most people.				
16	I have a hard time keeping pace with my friends.				

Appendix VIII B

Hausa language translated copy of ISEF-SF16

Interpersonal Support Evaluation List-Short Form

Lamba _____

Umurni

Wannan littafin yana kunshe da tambayoyi wadda zai dace ko rashin dacewa da kai/ke. A kowanne tambaya zami amsa da yadace da kai/ke

S/No	Tambayoyi	Shakka bahakaba	Watakila bahakaba	Watakila hakane	Shakka hakane
1	Akwai a kalla mutum ɗaya wanda na sani nake gaskantawa and amincewa da gargadinsu				
2	Babu ɗaya mutun da nake iya amince da su game shawarwarin ko mu'amula kan kuɗi				
3	Babu ɗaya mutun da nake iya ba ni haƙiƙani shawarwari akan yadda kake magance matsaloli				
4	Lokacin da na bukatar shawarwari ga yadda zan magance matsalolina, inna da mutumin da zan iya juya zuwa				
5	Mutane basa sun gayyata cikin al'amuransu				
6	Lokacin da na ji kadaitaka, akwai mutane da dama da zan iya kira mu tattauna magana				
7	A kullum inna haduwa da tataunaw da 'yan'uwana da abokai				
8	Ina jin cewa ina kan Geza na da'irar abokai				
9	Idan zanyi tafiya na 'yan makonni, inna da wani wanda zai kullamin da gidana a baya na				
10	Idan na kasance banda lafiya da kuma ina bukatar zuwa gani likita, ina da matsala samun wani da zai taimakamin				
11	Idan na kasance da lafiya, banda wanni wanda zan iya samu ya taya ni da hidima ko aiyuka yau da kullum				
12	Idan ina da wani muhimmin wasika a gidan wasiku kamar biyar. in kuma ba zan iya zuwaba, ina da wanda zai iya yi a madadina				
13	Mafi yawan abokaina sun fini samun nasara a yin canje-canje a cikin rayukansu fiye da ni				
14	Mafi yawan abokaina sunfi ban sha'awa fiye da ni				
15	Nafi gamsu da rayuwa fiye da mafi yawan mutane				
16	Ina da matsalar kiyayye taki tare da abokaina				

Appendix IX

A. Summary of log₁₀ normality for the transformation of the variables

N= 443

Variables	No items	<u>Before transformation</u>		<u>After transformation</u>	
		Skewness (SE)	Kurtosis (SE)	Skewness (SE)	Kurtosis (SE)
General health	1	-0.122 (0.116)	0.0365 (0.231)		
Symptoms score	5	0.005 (0.116)	-0.059 (0.231)		
Global PROQOL score	43	0.00023 (0.116)	-0.036 (0.231)		
Health concern (worries)	4	0.431 (0.116)*	0.168 (0.231)	-2.253 (0.116)*	7.475 (0.231)*
Lipodystrophy (body change)	4	0.071 (0.116)	-0.648 (0.231)*	-2.423 (0.116)*	-5.761 (0.231)*
Physical and cognitive functioning	4	0.319 (0.116)*	-0.461(0.231)	-2.369 (0.116)*	7.293 (0.231)*
Social support	16	0.114 (0.116)	1.940 (0.231)*	-6.452 (0.116)*	89.485 (0.231)*
Emotional distress	3	0.216 (0.116)	-0.677 (0.231)*	-2.585 (0.116)*	8.979 (0.231)*
Treatment impact	10	-0.673 (0.116)*	0.481 (0.231)*	-2.834 (0.116)*	6.325 (0.231)*
Intimate relationship	4	0.561 (0.116)*	-0.700 (0.231)*	1.263 (0.116)*	0.555 (0.231)*
Stigmatisation	2	1.256 (0.116)*	1.548 (0.231)*	-0.205 (0.116)	-1.703 (0.231)*
Spirituality (coping)	1	-0.576 (0.116)*	-0.339 (0.231)	-3.383 (0.116)*	12.081 (0.231)*
Financial difficulties	1	-0.464 (0.116)*	-0.373 (0.231)	-4.469 (0.116)*	20.536 (0.231)*
Future	1	-1.011 (0.116)*	-0.058 (0.231)	-2.818 (0.116)*	6.962 (0.231)*
Social relationships	2	-0.586 (0.116)*	-0.381 (0.231)	-4.130 (0.116)*	28.136 (0.231)*
Satisfaction with the health care	1	15.375 (0.116)*	294.609 (0.231)*	-5.622 (0.116)*	38.831 (0.231)*

Note: * data is significantly skewed or kurtoses that is, statistic is more than twice its standard error to determine if the skewness or kurtosis were significant

B. Summary of square root normality for the transformation of the variables

N= 443

Variables	No items	Before transformation		After transformation	
		Skewness (SE)	Kurtosis (SE)	Skewness (SE)	Kurtosis (SE)
General health	1	-0.122 (0.116)	0.0365 (0.231)		
Symptoms score	5	0.005 (0.116)	-0.059 (0.231)		
Global PROQOL score	43	0.00023 (0.116)	-0.036 (0.231)		
Health concern (worries)	4	0.431 (0.116)*	0.168 (0.231)	-0.717 (0.116)*	1.192 (0.231)*
Lipodystrophy (body change)	4	0.071 (0.116)	-0.648 (0.231)*	-1.144 (0.116)*	1.425 (0.231)*
Physical and cognitive functioning	4	0.319 (0.116)*	-0.461 (0.231)*	-0.806 (0.116)*	1.402 (0.231)*
Social support	16	0.114 (0.116)	1.940 (0.231)*	-2.00 (0.116)*	20.453 (0.231)*
Emotional distress	3	0.216 (0.116)	-0.677 (0.231)*	-0.838 (0.116)*	-1.169 (0.231)*
Treatment impact	10	-0.673 (0.116)*	0.481 (0.231)*	-1.365 (0.116)*	4.029 (0.231)*
Intimate relationship	4	0.561 (0.116)*	-0.700 (0.231)*	-0.433 (0.116)*	-0.624 (0.231)*
Stigmatisation	2	1.256 (0.116)*	1.548 (0.231)*	0.300 (0.116)*	-1.271 (0.231)*
Spirituality (coping)	1	-0.576 (0.116)*	-0.339 (0.231)	-1.824 (0.116)*	4.049 (0.231)*
Financial difficulties	1	-0.464 (0.116)*	-0.373 (0.231)	-1.813 (0.116)*	5.322 (0.231)*
Future	1	-1.011 (0.116)*	-0.058 (0.231)	-1.938 (0.116)*	3.225 (0.231)*
Social relationships	2	-0.586 (0.116)*	-0.381 (0.231)	-1.518 (0.116)*	4.080 (0.231)*
Satisfaction with the health care	1	15.375 (0.116)*	294.609 (0.231)*	1.863 (0.116)*	53.600 (0.231)*

Note: * data is significantly skewed or kurtoses that is, statistic is more than twice its standard error to determine if the skewness or kurtosis were significant

Appendix X

A. Item loading to assess dimensionality of seven selected PROQOL-HIV questionnaire subscales

1. Item loading for treatment impact (N=443)

S/No	Items	Factor loadings
1	Having to take my HIV medicine everyday has bothered me	0.508
2	I have been satisfied with my HIV medicine	0.417
3	I have been bothered by the side effects of my HIV medicine	0.548
4	The size of the pills has bothered me	0.832
5	The number of pills per day has bothered me	0.674
6	I have been bothered by the number of times I have had to take my HIV medicine each day	0.783
7	I have had to hide in order to take my HIV medicine	0.457
8	I have felt like changing my HIV medicine	0.667
9	Because of my HIV medicine, I have had difficulty going out with my friends or family	0.640
10	I have forgotten to take my HIV medicine	0.400

2. Item loading for emotional distress (N=443)

S/No	Items	Factor loadings
1	I have been sad	0.740
2	I have been anxious	0.721
3	I have been more irritable	0.671
4	I have been depressed	0.640

3. Item loading for symptoms score (N=443)

S/No	Items	Factor loadings
1	I have been bothered by digestive problems (stomach ache, bloating, diarrhoea, nausea or vomiting)	0.588
2	I have been bothered by pain	0.726
3	I have had a poor appetite	0.655
4	I have had difficulty sleeping	0.743
5	I have felt tired	0.521

4. Item loading for intimate relationship (N=443)

S/No	Items	Factor loadings
1	I have had difficulty with my love life	0.782
2	My sexual desire has diminished	0.618
3	I have felt restricted in my sexual activities	0.702

5. Item loading for lipodystrophy (N=443)

S/No	Items	Factor loadings
1	I have been bothered by a change in weight	0.516
2	I have been bothered by skin problems (dry skin, itching, rash)	0.478
3	I have been bothered by changes in my body shape (sunken cheeks, thinner legs or arms, smaller buttocks, larger chest or breast, fat belly, fat at the back of the neck)	0.497
4	I have been unhappy with my physical appearance	0.548

6. Item loading for health concern (N=443)

S/No	Items	Factor loadings
1	HIV was on my mind	0.596
2	I have worried about the results of my follow-up tests such as viral load or T cells	0.490
3	I have been afraid that my disease will get worse one day	0.667
4	I have been afraid of catching infections	0.454

7. Item loading for physical and cognitive functioning (N=443)

S/No	Items	Factor loadings
1	I have had difficulty concentrating or paying attention	0.603
2	I have had problems with my memory	0.618
3	I have had difficulty with daily activities	0.772
4	I have had difficulty with strenuous physical activities such as carrying heavy objects, running or walking a long distance, climbing several flights of stairs	0.744

B. Goodness-of-fit of emotional distress, symptoms score, physical and cognitive functioning, health concern, lipodystrophy, treatment impact and intimate relationship (N=443)

Subscale	α - value	χ^2	CFI	RMSEA	<i>p</i> - value
Emotional distress	0.806	345	0.899	0.061	0.051
Treatment impact	0.901	468	0.801	0.062	0.059
Health concern	0.854	351	0.901	0.058	0.062
Symptoms score	0.801	431	0.804	0.060	0.060
Physical and cognitive functioning	0.912	453	0.902	0.051	0.070
Lipodystrophy	0.882	467	0.903	0.052	0.069
Intimate relationship	0.816	435	0.912	0.050	0.064

Appendix XI



Draft of interview questions for the qualitative aspect of the research

This is an indication of the questions that will be asked in the in-depth interview. The precise order and wording of the questions may vary depending on how each interview progresses. The purpose of this research is to understand how HIV impacts on your quality of life. There are no right and wrong answers. You can ask for the interview to be stopped at any time. With your permission, I will like to tape the interviews so as to have a better record of what they you.

1. How old are you?
2. Where do you live?
3. Who do you live with?
4. When were you diagnosed with HIV? And what was your reaction?
5. Can you tell me about what it's like living with HIV?
6. Do you feel that having HIV has an impact on your life?
 - a. In what ways?
 - b. What are the things/aspects of your life that are affected by HIV?

Prompts: family life, work, daily activities, physical and mental well-being, sexual behaviour, finances, and anything else you can think of that you are interested in. This is the central question.
7.
 - a. What would you say are the most important things in your life at the moment?
 - b. How is this different to things that were important to you before you were diagnosed with HIV?
8. What do you think QoL means?
9. Some people also say there have been positive aspects about their diagnosis, would you agree with that? (If yes)
 - a. Can you tell me what some of these positive experiences have been?
 - b. And what about the more negative aspects of HIV. Can you tell me about some of those?
10. How does the insecurity/insurgency/Boko Haram affect your QoL, health and access to your HIV treatment?

Appendix XII



PARTICIPANT'S INFORMATION SHEET FOR THE QUALITATIVE RESEARCH

Title of Project: **Assessing health-related quality of life of people infected with HIV/AIDS in Maiduguri, Nigeria**

Thank you for considering to participate in this research project to assess the **health-related quality of life of people infected with HIV/AIDS in Maiduguri, Nigeria**. The purpose of the study is to examine the impact of HIV on the quality of life of people infected with HIV and explore the in-depth understanding and meaning of quality of life of HIV infected persons in Nigeria. The information that you provide will contribute to my PhD Research Project taking place at The University of Essex, UK. The project will also help to improve services for HIV care in Nigeria. The project has received ethical approval from the University of Essex and University of Maiduguri Teaching Hospital Ethics Committee, Maiduguri, Nigeria and is being supervised by Prof Gill Green and Dr Sheila Black of the University of Essex, UK. Your participation is entirely voluntary and will have no impact on the treatment or care you receive.

What will happen:

A small number of the participants will be asked to discuss their lived experiences and views on being infected with HIV. These discussions will be recorded, and later transcribed and anonymised, and sections of them may be used in a published PhD thesis. Discussions can last as long as you wish; although typically it is asked that you allow an hour or so of your time – to ensure that there is ample time to listen to all that you have to say!

Participants' rights:

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed. In addition, you have the right to omit or refuse to answer or respond to any question that is asked of you if you so wish.

You have the right to have your questions about the procedures answered (unless answering these questions would interfere with the study's outcome). If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins. However, if you choose not to take part in the study this will in no way affect the HIV treatment you are currently receiving.

Benefits and risks:

There are no known benefits or risks for you in this study. However, the results may help to improve HIV care services.

Cost, reimbursement and compensation:

Your participation in this study is voluntary.

Confidentiality/ anonymity:

The data collected does not contain any personal information about you such as name and address except sex, marital status and age. The data obtained will be stored privately by password protecting the research database. The data will only be shared among the principal investigators (the student and the academic supervisors). Tapes and hard copies of materials (transcripts) will be stored in my locked cabinet.

For further information:

Please contact: **Ismaila Saidu** – mobile phone: +447586592526 (UK number) and +2348148060361 (Nigerian number) email: iasaid@essex.ac.uk – who will be glad to answer your questions about this study at anytime.

Appendix XIII



CONSENT FORM FOR QUALITATIVE RESEARCH

Title of Project: **Assessing health-related quality of people infected with HIV/AIDS in Maiduguri, Nigeria**

Name of Researcher: **Ismaila Saidu**

PLEASE INITIAL ALL BOXES

1. I confirm that I have read and understand the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that anonymised relevant sections of my data collected during the study may be looked at by individuals from the University of Essex and I give permission for these individuals to have access to my anonymised data.

4. I understand that, and consent to, some of my discussions with researchers being recorded and sections of the anonymised transcripts being published in the project report.

5. I agree to take part in the above study.

Name of Participant:..... Signature:..... Date:.....

Name of Person taking consent:.....Signature..... Date:.....

Appendix XIV

Summary of the emerged themes during the stages of the qualitative framework data analysis

A. Thematic framework identification

(10 codes were initially generated according to how the participants responded to the questions asked)

1. Participants reaction when diagnosed with HIV
5. Experience living with HIV
6. Impact HIV on Well-being (eg family life, work, daily activities, physical and mental well-being, sexual behaviour, finances, and others)
7. Important things in life after HIV diagnosis (including differences between before and after diagnosed with HIV)
8. Meaning of QoL
9. Positive aspects about HIV diagnosis
10. Negative aspects of HIV diagnosis
11. Effect of insurgency on QoL
12. Effect of insurgency on access to HIV care
13. Effect of insurgency on Health

B. Indexing phase

(The initial 10 codes generated were broken down into 17 sub-codes)

1. Adherence of ARVs
2. Effect of CD4+ count on symptoms
3. Coping
4. Effect of Symptoms on physical health
5. Experience living with HIV
6. Health concern
7. Impact of ART
8. Impact of HIV on well-being
9. Meaning of QoL
10. Impact of insecurity on QoL
11. Impact of insecurity on access to HIV care
12. Impact of insecurity on Health
13. Important things in life
14. Reaction to HIV diagnosis
15. Stigmatisation and disclosure
16. HIV transmission
17. Counselling

C. Charting process

Eight broad themes were generated

Finally, 6 broader themes and five sub-themes were generated after further assessment

Initial eight broad themes:

1. QoL is more than being free of disease
2. Impact of HIV on well-being
3. Stigmatisation
4. Playing with ART
5. Coping strategies
6. Impact of insecurity on health, HIV care and QoL
7. Health concern
8. Reaction to diagnosis

Final six broader themes:

1. QoL is more than being free of disease
2. Impact of HIV on well-being (and five sub-themes under it)
3. Stigmatisation
4. Playing with ART
5. Coping strategies
6. Impact of insecurity on health, HIV care and QoL