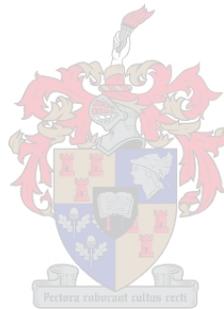


**SPIRITUAL CARE TO PEOPLE LIVING WITH HIV AND AIDS  
WITHIN THE CONTEXT OF THE REFORMED CHURCH OF  
EAST AFRICA'S PLATEAU MISSION HOSPITAL (KENYA)**

**By**

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(CLINICAL PASTORAL CARE - HIV/AIDS)  
AT THE UNIVERSITY OF STELLENBOSCH**

**SUPERVISOR: Prof. D.J. LOUW**

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## DECLARATION

I, the undersigned, hereby declare that this long essay is my original work prepared through my personal reading, scientific research methods and critical reflection. I have not previously submitted this project, in its entirety or in part, at any university for any degree.

**SIGNED** -----

**DATE**-----

## **DEDICATION**

To  
My loving husband and friend,  
Chosefu Chemorion,  
who stood by me as my firm mentor,  
and also our dear children,  
Chebeni  
Kiptengwer  
Cheruto  
and  
Chebet  
who endured the absence of a mother  
as I undertook full-time studies.

## **ABSTRACT**

### **SPIRITUAL CARE TO PEOPLE LIVING WITH HIV AND AIDS WITHIN THE CONTEXT OF THE RCEA PLATEAU MISSION HOSPITAL (KENYA)**

**By Edith Khakasa Chemorion**

The basic premise of this study is that a spiritual approach to care and support of people living with HIV, by means of a holistic pastoral model, would provide the Reformed Church of East Africa's Plateau Mission Hospital with an integrated dimension in their community-based care programme for people living with HIV/AIDS. This will go a long way in assisting the RCEA's diversification of the existing medical model, particularly in the Plateau Mission Hospital's catchment area with its ever-increasing cases of infections, deaths, rejections, church-related stigma, orphans and vulnerable children.

The researcher proposes the use of a spiritual model in dealing with PLWH in the Plateau Mission Hospital because this will help to address some of the unresolved theological issues that come to the fore when addressing matters concerning the health and illness of people living with HIV and AIDS. The researcher does this with acute awareness of the importance of integrating other approaches in the care and support of PLWH. For a holistic approach to be effected, the social development, medical, psychological and holistic systemic approaches to care must be considered. The holistic systemic approach used by the biomedical personnel and other caregivers should regard the person as a relational and social being acting within a cultural context.

On the other hand, the biomedical model serves us with accurate diagnoses and sophisticated methods of treatment within which modern medicine is practiced. Similarly, the psychosocial model considers the influence of the social environment not only to the challenges that PLWH face, but also on the care they should receive. However, research has shown that there is an increasing need for holistic care in health care systems. This calls for the inclusion of spirituality within the developing bio-psycho-social approaches in addressing health and illness, particularly for people living with HIV and AIDS, in order for them to attain holistic healing.

Plateau Mission Hospital, being a church-based institution within the jurisdiction of the RCEA's southern presbytery, can be an effective vehicle for pastoral care of people living with HIV and AIDS. The organization is strategically placed and has the capacity (resource persons) to engage in a holistic ministry. The paper also aims at unlocking the RCEA's resources to become more

involved in all rounded existential issues of PLWH in the hospital's catchment area.

In this study, it is presupposed that, although the Hospital has a history of medical and social development work and chaplaincy office, it lacks emphasis on the spiritual dimension, and yet this focal point is important in terms of the immediate HIV/AIDS context at Plateau. The researcher established that the training that the personnel at the medical facility have undertaken promotes a clinical approach to all issues of health (prevention and treatment after prescription), even to people living with HIV/AIDS.

### **Methodology.**

The first methodology for data collection that the research employed was literature review. In this case, library and church documents were reviewed to gather information on related matters. The areas reviewed were related to spirituality, care and healing in the context of HIV, pastoral care and theology in the context of HIV, and biomedical approaches in relation to the care of PLWH, and documentation (Plateau Hospital Reports, the RCEA's constitution and Care Departmental Reports) on the RCEA's approach to Hospital care to PLWH by means of the CBHC programme at the Plateau Mission Hospital in Eldoret. The websites were also consulted for purposes of data collection.

The second method was conducting specific oral and written interviews with the Hospital's CBHC staff, PLWH, congregational and church leadership on matters of the proposed spiritual care of PLWA. The areas interviewed were for the spiritual needs, those involved in the care and support of PLWH, improving existing interventions, the challenges encountered in the care for PLWH, the unfulfilled needs of PLWH and how spiritual care could improve the quality of the lives of PLWH.

The third method of data collection was participant observation. The researcher was involved in the activities being studied. This method entailed participant observation during normal diaconal care activities in the RCEA's Plateau parish congregations that the researcher implemented, for instance visiting people living with HIV/Aids, taking gifts to children affected by HIV. In meeting with volunteer caregivers during visits, while joining the CBHC team during follow-up meetings with PLWH in their homes, data was collected. The researcher had patient consultation during days for voluntary counseling and testing and informal meetings with volunteer caregivers.

## **Presentation of the Thesis - Outline of Research**

This study is divided into five parts. **Chapter 1** will examine the background to the study considering the problem statement, research questions, research objectives, hypothesis, justification, the scope of the research, the methodology used, limitations and delimitations.

In **Chapter 2** the paper will explore The Kenyan Scenario: Medical work and the involvement of the church within the community. This will cover the Kenyan national HIV updates, Uasin Gishu updates, Ainabkoi divisional statistics, the background to the Reformed Church of East Africa, Plateau Mission HIV ministry covering the psycho-social approach to community-based care of CBHC in the Reformed Church of East Africa in the Plateau Hospital catchment area. The paper will examine the medical care offered to people living with HIV/AIDS, such as the treatment of opportunistic diseases, administration of anti-retroviral drugs and the prevention of mother-to-child transmission and voluntary counseling and testing. The paper will also examine the social and developmental activities and services rendered to PLWA and the orphans and vulnerable children by means of compassionate care. CBHC networking with congregations, and Moi Teaching and Referral Hospital will also be highlighted. The paper will also highlight the gaps experienced as a result of the focus on medical and social developmental approaches to the care and support of PLWA and OVCs.

**Chapter 3** is largely the analysis of interview responses, and presents the findings of field research at the RCEA Plateau Mission Hospital's selected area of study. This will indicate the seriousness of the unattended needs in this case the spiritual needs and the magnitude of the problem in the health facility but, by implication, affecting the church. This will need a change of stance, namely that of regarding HIV as a medical problem that the hospital needs to address, and view it as a collective need for all key players in church, hospital and community.

**Chapter 4** will look at the challenge HIV poses to the spiritual care of PLWH in Plateau Mission Hospital. The chapter will contain a literature review on the holistic approach in the care and support of people living with HIV. The section will look at understanding the needs of people living with HIV, pastoral care of people living with HIV, practical theology, biomedical and bio-psycho-social models in the care of PLWH. The study will also examine the relevance of God-images, systems approach, the role of the church and a spiritual care approach in the holistic healing for PLWH by means of pastoral care.

**Chapter 5** will conclude the paper and will shed light on the importance of the proposed approach to be integrated into the current strategy (pastoral care model with a spiritual-care approach). It is hoped that the recommendations that will be made at the end will strengthen the high demand for a holistic-care ministry to people living with HIV and the affected families in the RCEA Plateau Mission Hospital.

## OPSOMMING

### **SPIRITUELE VERSORGING VAN MENSE WAT LEEF MET MIV EN VIGS BINNE DIE KONTEKS VAN DIE RCEA PLATEAU MISSION HOSPITAL (KENIA)**

**Deur Edith Khakasa Chemorion**

Die basiese uitgangspunt van hierdie studie is dat 'n spirituele benadering tot versorging en steun van mense wat leef met MIV/vigs, deur middel van 'n holistiese pastorale model, 'n geïntegreerde demensie sal voeg by die Plateau Mission Hospital van die Reformed Church of East Africa se gemeenskapsgebaseerde sorgprogram vir mense met MIV/vigs. Dit sal bydra tot die RCEA se diversifikasie van die bestaande mediese model, veral in die Plateau Mission Hospital se opvanggebied met sy immer-stygende aantal gevalle van infeksies, sterftes, verwerpings, kerkverwante stigma, wees- en weerlose kinders.

Die navorser stel voor die gebruik van 'n spirituele model in die hantering van mense wat leef met MIV/vigs (MWLM) in die Plateau Mission Hospital omdat dit sal bydra tot die aanspreek van sommige van die onopgeloste teologiese kwessies wat na vore kom wanneer gekyk word na sake wat verband hou met die gesondheid of ongesondheid van mense wat met MIV en vigs leef. Die navorser is deurgaans akuit bewus van die belang daarvan om ander benaderings te integreer in die sorg en steun van MWLM. Om 'n holistiese benadering teweeg te bring, moet die sosiale ontwikkeling, mediese, sielkundige en holistiese sistemiese benadering tot sorg oorweeg word. Die holistiese sistemiese benadering wat deur biomediese personeel en ander versorgers gebruik word, behoort die persoon te beskou as 'n relasionele en sosiale wese wat binne 'n kulturele konteks optree.

Aan die ander kant bied die biomediese model die akkurate diagnoses en gesofistikeerde behandelingsmetodes waarbinne moderne mediese sorg beoefen word. Die sielkundige model oorweeg weer die invloed van die sosiale omgewing – nie net op die uitdagings wat MWLM konfronteer nie, maar ook op die sorg wat hulle moet ontvang. Navorsing het egter getoon dat daar 'n toenemende behoefte aan holistiese sorg in gesondheidsorgstelsels is. Dit vra na die insluiting van spiritualiteit in die ontwikkelende bio-psigo-sosiale benaderings tot die aanspreek van gesondheid en ongesondheid, veral vir mense wat leef met MIV en vigs, sodat hulle holisties geheel kan word.

As kerk-gebaseerde instelling onder die jurisdiksie van die RCEA se suidelike ring, kan die Plateau Mission Hospital 'n effektiewe kanaal wees vir pastorale sorg van mense wat leef met MIV en vigs. Die organisasie is strategies geleë en het die kapasiteit (bronne, personeel) om betrokke te raak in 'n

holistiese bediening. Die tesis se doel is ook om die RCEA se bronne te ontsluit om meer betrokke te raak in alle geronde eksistensiële vraagstukke van MWLM in die hospitaal se opvanggebied.

In hierdie ondersoek word voorveronderstel dat, hoewel die hospitaal 'n geskiedenis het van mediese en maatskaplike ontwikkelingswerk en kapelaanskap, skiet dit tekort wat klem op die spirituele dimensie betref – al is hierdie sentrale punt belangrik in terme van die onmiddellike MIV/vigs konteks by Plateau. Die navorser het vasgestel dat die opleiding wat die personeel by die mediese fasiliteit onderneem, 'n kliniese benadering tot alle kwessies rondom gesondheid (voorkoming en behandeling na voorskrif) bevorder – selfs teenoor mense wat met MIV/vigs leef.

Die eerste metodologie vir data-versameling wat gebruik is, was bestudering van literatuur. In hierdie geval is biblioteek- en kerkdokumente bestudeer om relevante inligting in te win.. Die terreine wat bestudeer is, het verband gehou met spiritualiteit, sorg en heling in die MIV-konteks, pastorale sorg en teologie in die MIV-konteks, en biomediese benaderings tot die sorg van MWLM. Dokumentasie (Plateau Hospital-verslae, die RCEA se konstitusie en Care Departmental-verslae) oor die RCEA se benadering tot hospitalsorg vir MWLM deur middel van die CBHC program by die Plateau Mission Hospital in Eldoret is bestudeer. Inligting is ook verkry op Internet-webblaaie.

Die tweede metode was die voer van mondelinge en geskrewe onderhoude met die hospitaal se CBHC personeel, MWLM en gemeente- en kerkleiers oor sake wat verband hou met die spirituele sorg van MWLM. Daar is onderhoude gevoer oor die spirituele behoeftes, diegene betrokke by die sorg en steun van MWLM, verbetering van bestaande intervensies, die uitdagings van sorg vir MWLM, die onvervulde behoeftes van MWLM en hoe spirituele sorg die lewensgehalte van MWLM kan verbeter.

Die derde metode van dataversameling was deelnemende observasie. Die navorser was betrokke by die aktiwiteite wat bestudeer word. Hierdie metode behels deelnemer-observasie gedurende normale diakonale sorg-aktiwiteite in die RCEA se Plateau gemeentes wat die navorser geïmplementeer het, byvoorbeeld om mense wat met MIV/vigs leef, te besoek en om geskenke te neem vir kinders wat geaffekteer word deur MIV/vigs. Data is ook versamel tydens ontmoetings met vrywillige versorgers gedurende die CBHC span se opvolg-besoeke aan MWLM in hul tuistes. Die navorsers het op dae vir vrywillige toetsing en berading gekonsulteer met pasiënte en informele gesprekke gevoer met vrywillige versorgers.

## **Aanbieding van die tesis – oorsig van navorsing**

Die tesis is in vyf verdeel. **Hoofstuk 1** ondersoek die agtergrond tot die tesis en sluit in die probleemstelling, navorsingsvrae, navorsingsdoelstellings, hipoteses, verantwoording, die bestek van navorsing, die metodologie wat gebruik word, beperkings en afbakening. .

In **Hoofstuk 2** ondersoek die tesis die psigo-sosiale benadering tot gemeenskapsgebaseerde sorg van MWLM in die Plateau Hospital opvanggebied van die Reformed Church of East Africa . Die tesis ondersoek die mediese sorg wat gebied word vir mense wat met MIV/vigs leef, soos die behandeling van opportunistiese siektes, toediening van anti-retrovirale middels, die voorkoming van ma-tot-kind oordrag en vrywillige berading en toetsing. Die tesis kyk ook na die sosiale en ontwikkelings-bedrywighede en dienste wat gelewer word aan MWLM en aan wees- en weerlose kinders deur barmhartige sorg van CBHC netwerke met gemeentes. Moi Teaching en Referral Hospital kry ook aandag. Die tesis wys veral op die leemtes wat ervaar word as gevolg van die fokus op mediese en sosiale ontwikkelingsbenaderings tot die sorg en steun van MWLM en wees- en weerlose kinders

**Hoofstuk 3** is grootliks 'n analise van die onderhoud-reaksies, en bied die bevindinge van veldnavorsing by die RCEA Plateau Mission Hospital se gekose gebied van ondersoek. Dit dui aan hoe ernstig die behoeftes is wat nie aangespreek word nie – in hierdie geval die spirituele behoeftes. En hoe groot die omvang van die probleem in die gesondheids-instansie is wat, per implikasie, ook die kerk affekteer. Dit vra dus na 'n verandering in benadering, naamlik van MIV/vigs as 'n mediese probleem beskou wat die hospitaal moet aanspreek, na dit beskou as 'n kollektiewe behoefte aan die insette van alle sleutel-rolspelers in kerk, hospitaal en gemeenskap.

**Hoofstuk 4** bevat 'n literatuur-oorsig van die holistiese benadering tot die sorg en steun van mense wat leef met MIV/vigs. Dié afdeling kyk na begrip vir die behoeftes van mense wat leef met MIV/vigs, praktiese teologie, biomediese en bio-psigo-sosiale modelle in die sorg van MWLM. Die studie ondersoek ook die relevansie van 'n spirituele sorg-benadering in die holistiese heling van MWLM deur pastorale sorg.

**Hoofstuk 5** sluit die tesis af en werp lig op die belang daarvan dat die voorgestelde benadering geïntegreer word met die huidige strategie (pastorale sorg model met 'n spirituele sorg benadering). Hopelik sal die aanbevelings aan die einde die dringende vraag na 'n holistiese sorg-bediening vir mense wat leef met MIV/vigs en die geaffekteerde gesinne en families in die RCEA versterk.

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To all those who encouraged me, and gave me insights on both practical and theoretical issues on clinical pastoral care and biomedical care of people living with HIV and AIDS but are not mentioned here: May the Lord bless you all.

".... for I was hungry and you gave me food,  
thirsty and you gave me something to drink,  
a stranger and you welcomed me,  
naked and you gave me clothing,  
I was sick and you took care of me.  
Truly I tell you, just as you did it to the  
least of your brothers and sisters,  
you did it to me" (Matt. 25:35-40).

## ABBREVIATION / ACRONYMS AND TERMS

<b>AAMC</b>	Association of American Medical Colleges
<b>AIDS</b>	Acquired immune deficiency syndrome
<b>AMPATH</b>	Academic Model for Prevention and Treatment of HIV & AIDS
<b>AMS</b>	American Medical Schools
<b>ART</b>	Anti-retroviral therapy
<b>ARV</b>	Anti-retroviral
<b>BPS</b>	Bio-psycho-social
<b>BPS+S</b>	Bio-psycho-social and spiritual
<b>CBHC</b>	Community-based health care
<b>CVCG</b>	Church volunteer care-givers
<b>HIV</b>	Human immuno-deficiency virus
<b>HRSA</b>	Health Resource and Services Administration
<b>IRM</b>	Infant mortality rate
<b>LWF</b>	Lutheran World Federation
<b>MTRH</b>	Moi Teaching and Referral Hospital
<b>OI</b>	Opportunistic infections
<b>OVC</b>	Orphans and vulnerable children
<b>PLWH</b>	People living with HIV
<b>PLWHA</b>	people living with HIV and AIDS
<b>PLWA</b>	People living with Aids
<b>PMTCT</b>	Prevention of mother-to-child transmission
<b>RCEA</b>	Reformed Church of East Africa
<b>ST</b>	Steering Committee
<b>VCT</b>	Voluntary Counseling and testing
<b>VVCG</b>	Village volunteer care-givers

# CONTENTS

<b>DECLARATION .....</b>	<b>II</b>
<b>DEDICATION .....</b>	<b>III</b>
<b>ABSTRACT .....</b>	<b>IV-VII</b>
<b>OPSOMMING .....</b>	<b>VIII-XI</b>
<b>ACKNOWLEDGMENTS.....</b>	<b>X III</b>
<b>ABBREVIATIONS .....</b>	<b>XIV</b>
<b>TABLE OF CONTENTS .....</b>	<b>XV-XII</b>
<b>CHAPTER 1: BACKGROUND TO THE STUDY</b>	
1.1 Introduction.....	1
1.2 Location of the study.....	1-2
1.3 Reformed Church of East Africa Medical Department.....	2
1.4 Problem statement.....	2-5
1.5 Research Problem.....	5
1.6 Research objectives.....	5
1.7 Research questions.....	5
1.8 Hypothesis.....	5
1.9 Justification.....	6-8
1.10 Scope and Methodology.....	8
1.10.1 Scope of Research.....	8
1.10.2 Data collection Methods, Analysis and Presentation.....	8-10
1.10.2.3. Questionnaire.....	10-11
1.10.3 Data Analysis and Presentation.....	11
1.10.3.1 Data analysis.....	11-12
1.10.3.2.Charts.....	12
1.10.3.2.3 Tables.....	12
1.10.3.4 Figures.....	12
1.10.3.5 Map(s).....	12
1.11 Research Design.....	12
1.12 Limitations and Delimitations.....	13

1.12.1	Limitations.....	13
1.12.2	Delimitations.....	13

**CHAPTER 2: THE KENYAN SCENARIO: MEDICAL WORK AND INVOLVEMENT OF THE CHURCH WITHIN THE COMMUNITY**

2.1	Introduction.....	14
2.1.1	The Latest updates on the HIV/AIDS status in Kenya.....	15
2.2	The Uasin Gishu District HIV/AIDS Updates.....	15-17
2.3	Background information: Reformed Church of East Africa .....	17
2.3.1	The RCEA organizational structure.....	17-18
2.3.2	Establishment of the RCEA.....	18
2.3.3	Medical work of the RCEA.....	18-19
2.4	Location of study.....	20-21
2.4.1	Structure of the RCEA Plateau Hospital CBHC & Background.....	21-25
2.4.2	The main objectives - CBHC.....	25
2.5	Services offered by CBHC to the Plateau community.....	26
2.5.1	Voluntary counseling and testing.....	26
2.5.2	Prevention of mother-to-child transmission.....	26
2.5.3	The Resource Centre.....	26-27
2.5.4	Active home-based Health Care.....	27
2.5.5	The Referral Services.....	27-28
2.5.6	The OVC project.....	28
2.5.7	Nutritional Programme.....	28
2.5.8	Hospital Chaplaincy.....	28-29
2.6	The CBHC HIV/AIDS needs and service assessment.....	29-31
2.7	Concluding remarks.....	31-32

**CHAPTER 3: A PASTORAL ASSESSMENT AND FIELD DESCRIPTION OF THE RCEA PLATEAU MISSION HOSPITAL**

3.1	Introduction.....	33
3.2	Findings: preliminaries, presentation and analysis.....	34-35
3.2.1	The RCEA plateau Mission Hospital Interview plan.....	35-38
3.2.2	Real interview Responses.....	38-44

3.2.3	Data Analysis and presentation.....	44-46
3.4	Evaluation.....	46-47
3.5	Concluding remarks.....	47-52

**CHAPTER 4: HIV/AIDS AS A CHALLENGE TO SPIRITUAL CARE:**

**THE QUEST FOR MEANING AND DIGNITY**

4.1	Introduction. The challenge of HIV/AIDS: A Holistic Approach.....	53
4.2	The Impact of HIV/AIDS and the Challenge of Silence, Stigma and Discrimination.....	54-56
4.3	The biomedical model to health care of PLWH.....	56-59
4.4	The bio-psycho-social model of health and illness.....	59-60
4.4.1.	A new understanding in medicine. Bio-psycho-social and spiritual.....	60-61
4.5	A holistic systemic model to care of PLWH.....	61-62
4.6	Inter-disciplinary approaches to care giving.....	62-63
4.7	Practical theology defined.....	63-64
4.8	Pastoral Theology.....	64
4.9	Pastoral care to PLWH and the affected families.....	64
4.10.	Pastoral care and counseling.....	65-66
4.10.1	Counseling as a way of Caring for PLWH.....	66-67
4.11	Understanding PLWH and the affected Families.....	67-69
4.12	Spiritual care as an important part of pastoral care to PLWH.....	70-71
4.13	God Images among PLWH: The role of belief systems in therapy.....	71-74
4.14	Spiritual Care Model to the Care of PLWH and the affected families.....	74-78
4.15	The church and ministry to PLWH.....	78-80
4.16	Concluding remarks.....	80-82

**CHAPTER 5 : CONCLUSION AND RECOMMENDATIONS**

5.0	Conclusion.....	83-85
5.1	Recommendations .....	85-88

APPENDICES.....	88
APPENDIX 1: Map of Kenya.....	89
APPENDIX 2: Map of the Uasin Gishu District.....	90
APPENDIX 3: The RCEA’s organizational structure.....	91
APPENDIX 4: The RCEA’s CBHC organizational structure.....	92
APPENDIX 5: Case study 1.....	93
APPENDIX 6: Case study 2.....	94
APPENDIX 7: Case study 3.....	95
APPENDIX 8: The CBHC’s questionnaires.....	96
Bibliography.....	97-100

## CHAPTER 1: BACKGROUND TO THE STUDY

### 1.1 Introduction

The research was done in Plateau Hospital. The study paid attention to the biomedical<sup>1</sup> approach in the HIV AIDS activities of Plateau Hospital. In 1957 this hospital was established as a mission hospital under the medical department of the Reformed Church of East Africa (RCEA) in Kenya (Constitution of the Reformed Church of East Africa: 1993: RCEA). In the RCEA Plateau Hospital, the HIV interventions are carried out by a Community-Based Health Care Programme (CBHC) that works with people living with HIV – widows, orphans and vulnerable children are organized in-groups. These groups are found in four locations: Kipsinende, Plateau, Kipchamo and Kaptagat, which are found in the Ainabkoi division, Uasin Gishu district, and the Rift Valley Province in Kenya.

### 1.2 Location of the study

Plateau Hospital covers the four locations of the Ainabkoi Division in the Uasin Gishu District. Plateau Mission Hospital is situated in the Plateau region, which is located in the Rift Valley Province, the Uasin Gishu district, Ainabkoi division, Kipsinende location in Kenya. The area is relatively flat. Usually, the temperature during the day is between 18°C and 24°C. In this area, May to September are the wettest months. Before May and after September, it is normally dry and very windy. According to the 1999 Census Report (CBHC. 2003: Report: Plateau) this area has a population of 30,000. Most of these residents are small-scale farmers who grow wheat, maize and beans, a considerable proportion are brewers, and a few are small-scale business people. The RCEA Plateau Mission Hospital is the main health facility in the area, but there are

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<sup>1</sup> The Biomedical approach to health care is the approach used by medical personnel in medical care of patients. In this approach, the physician is concerned with diet, pain, history, and familial incidence, while considering empirical signs and symptoms as paramount. Diagnosis is done after presentation and this involves objective laboratory tests and the monitoring of vital signs, such as temperature, pulse and blood pressure, which would form the sole basis of any finding. For therapy to take place, the doctor prescribes a medical plan for the patient, based on the biological etiology and pathogenesis. The entire programme used in Plateau hospital for the inpatients, out-patients, and those under the home based CARE programme is guided by the medical skills and knowledge of the nursing personnel. For the CBHC work with PLWH and the affected families, formal medical procedures are followed. This limits the staff at Plateau to attend to psychosocial needs of PLWH and the affected families, but leaving the spiritual and related needs unattended to.

also private clinics. In the area there are government primary schools, secondary schools and a theological institution of the RCEA.

### **1.3 The Reformed Church of East Africa(RCEA) Medical Department.**

The Medical Department of the RCEA was started in 1954 as a small dispensary. By 1999, the department had expanded its area of operation to include Uasin Gishu, Nandi, Trans Nzoia, West Pokot, and the Turkana districts in Kenya. Preventive medicine was dispensed via mobile clinics. The hospital's income consists mostly of patients' fees, as well as grants from the Reformed Mission League in the Netherlands.

### **1.4 Problem Statement**

Since 2003, through the mission hospital, the RCEA has alleviated the suffering of people living with HIV/AIDS. The CBHC programme of the Plateau Mission Hospital has expanded their services from home-based care of people living with HIV/AIDS and their families, to the care and support of orphans and vulnerable children within the hospital's catchment area.

The 'initial response'<sup>2</sup> of the hospital was very much appreciated by the community. This entailed reaching out to people in the hospital's area, who had lost contact with others in the community, the church and their families. Among the pioneer PLWH (people living with HIV), some were rejected by their family and members of the congregation; others were stigmatized by members of the community (Appendix5, 6, 7).

Although medical and social care programmes developed towards community-based care and support of the PLWA, orphans and vulnerable children (OVC), the PLWH, OVC and the affected, who receive psychosocial support from CBHC staff and the village volunteer caregivers, are still discriminated against in families and communities. They are despised, avoided, and are viewed as bad people and, in some of the worst scenarios, women and children

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<sup>2</sup> During visitations organized by CBHC staff – in which the researcher participated – people living with HIV in the Plateau Hospital's catchment area, reported that the support from the hospital came at a time when PLWH and their families needed them. The hospital staff visited them, ensured that they got ARV drugs and received treatment for opportunistic infections at the Moi Teaching and Referral Hospital in Eldoret.

have their property removed (CBHC: 2008). Stigmatization of PLWH is still alive: some PLWH are rejected in some sections of the church, whereas some of these people experience no love, compassion or care from their families and communities. Some orphans and vulnerable children are lonely, have to take up adult roles and drop out of school when their parents die. PLWH and OVC experience a lot of anger. Communities and some members from congregations believe that God is punishing the PLWH for their wrongs. This makes the PLWH feel that they are unworthy, they isolate themselves and give up on life. For instance, there are some PLWH who have died soon after discovering that they had been infected with HIV that causes AIDS. Some women have experienced stigmatization from their own congregations and particularly from their marital homes soon after the death of their husbands. Below is a testimony given to the researcher in the field:

I was diagnosed with HIV in 1999. I became very sick in 2000 and was hospitalized and then discharged. Due to stigma, it was hard to find people to share my feelings with. I felt very lonely and condemned because most members of my congregation no longer visited me at home. Instead, they talked among themselves, saying that I was going to die soon. They alleged that I was infected with HIV because I was immoral and was getting a punishment from God.

*This client was infected by her husband who had multiple sex partners and practiced unprotected sex. She took Anti-Retro Viral Drugs and joined the support Group. (SUE: interview: July 2008. Plateau).*

One would expect that the RCEA, being a Christian organization, would employ spiritual care within pastoral care as central to their community-based care programme at Plateau. The researcher noted that in an attempt to implement both the theological and psychological models in the mission hospital, there has been a tendency to overlook the theological aspect and put more emphasis on the medical model. This was confirmed in an interview with CBHC staff who said that the medically trained co-ordinator, voluntary nurses, and village care givers use medical skills and knowledge in meeting the 'psychosocial needs'(CBHC:2008) of PLWH. With this strong emphasis on the medical and social development approaches in the Plateau Mission

Hospital, spiritual/religious and other related needs have been neglected.<sup>3</sup> This has led to more challenges that affect effective care of PLWH and OVC in the Plateau Hospital catchment area.

During community visits, the researcher established that pastors hardly address the burden of HIV/AIDS by sharing the information from the pulpit, nor encourage active congregational involvement or even share thoughts about compassionate care during mid-week prayer meetings. PLWH are still marginalized in the congregations despite being among Christians and members of the communities. The church does not have a strong stand on HIV/AIDS, hence this loophole for stigmatization, rejection and<sup>4</sup> condemnation. As a result OVC, PLWH and affected families give up hope inside and outside the church.

During community visits, discussions and interviews, the researcher realized that there were many people with anger<sup>5</sup> towards God, themselves and other people, i.e. those who were condemned and rejected by their families, those with no trace of hope for healing and with an uncertain future for themselves and their families. As, in the Plateau Hospital catchment area, the PLWH go through the asymptomatic, symptomatic, and full-blown terminal stages and moments of grief in their lives. They exhibit feelings of insecurity and loss, loss of families, friends, communities and the world.

The PLWH also struggle with unforgiveness, having their dignity<sup>6</sup> compromised, experiencing a great deal of turmoil from within and -out, suffering rejection, and experiencing loss due to their health condition.

Due to stigmatization<sup>7</sup> experienced by the PLWH and their affected families , the researcher is

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<sup>3</sup> CBHC: interview; November 2007: Eldoret). Psychosocial needs are the ones met by the CBHC team.

<sup>4</sup> See Adelaide's Case study in Appendix 6.

<sup>5</sup> This was number one spiritual issue raised by the co-ordinator in the project report of June 2008. Anger was one common challenge faced by those who go to church and those who are not churched at all.

<sup>6</sup> See Joses Case study.

<sup>7</sup> The PLWH and the affected families are discriminated against, despised, condemned in community and church (some examples in the stories in the case studies)

convinced that all these people need pastoral care and counseling that will offer understanding, unconditional love, compassion, hope, acceptance, reconciliation, comfort, empathy and God's message of salvation for them to find meaning within their existential experiences.

### **1.5 Research problem**

In order to address the issue of stigmatization experienced by the PLWH within the context of the Reformed church of east Africa Plateau Mission Hospital, the problem of the research is to develop a holistic approach in community based care which reckons with the spiritual dimension of care to PLWH. The guiding research question therefore is, “What should such a pastoral and spiritual approach entail within the setting of Plateau Mission Hospital?”

### **1.6 Research Objectives**

1. To describe the care and support given to PLWH and their affected families in Plateau Hospital catchment area, and
2. To explore the possibilities of implementing a holistic approach in community-based care for people living with HIV/AIDS by means of spiritual care in pastoral response.

### **1.7 Research questions**

1. What type of spiritual needs of the PLWH are met, or not met, through the care and support rendered by the Plateau Mission Hospital's CBHC programme?
2. What are some of the gaps and key stumbling blocks in the Plateau Mission Hospital's current strategy used in their care and support of PLWH that would require evaluation and integration to enhance the quality of care?

### **1.8 Hypothesis**

Due to the dominance of the medical approach in the response to people living with HIV some deeply felt needs of PLWH, such as spiritual needs, are not efficiently met. Hence the importance of a holistic model in pastoral care and support to PLWH. Such a spiritual approach to the care of

PLWH should supplement the medical model in order to provide a more holistic team approach. This will contribute to a safe space for disclosure at Plateau Mission Hospital. Such a holistic approach with the emphasis on the spiritual realm should introduce God-images that add to the process of destigmatization and the affirmation of human beings' dignity and identity beyond the restrictions of a merely social cultural hermeneutics.

## **1.9 Justification**

The impact of HIV/AIDS has had major effects on the life and mission of the hospital. The devastation caused by the pandemic should act as a wake-up call to the entire church. The continuous suffering of, and discrimination against PLWH, OVC and women -as shown in the case studies-despite being reached by the medical team at Plateau -as shown in the problem statement -are the motivating factors for this study. The hospital is encouraged to use another therapeutic paradigm, as the RCEA is challenged to examine the underlying contextual realities that promote stigmatization and discrimination in church communities; to join hands with hospital teams to address those realities in a way that can enhance inter-relatedness and connectedness for an assured support system towards holistic healing.

This will turn Plateau into a healing community with a safe space for disclosure and being involved in people's life experiences. The researcher is convinced that the proposed pastoral care model based on a spiritual approach for the care and support of PLWH and their affected families and communities, will help overcome the 'culture of silence'<sup>8</sup> in the hospital, church and communities. Moreso, it will help address issues of shame and stigma associated with HIV/AIDS, prejudice and injustices. By means of a spiritual approach, with strengthened support systems for children and adults infected and affected by HIV, the study sees the Plateau Hospital reducing stigma and affirming human dignity among the PLWH.

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<sup>8</sup> In plateau community which is Kalenjin, people are not willing to openly discuss HIV /AIDS. They associate HIV/AIDS with sex and matters of sex and sexuality are not discussed in the open. Men and women can not share discussions on sexuality. At the same time, HIV /AIDS has been linked with immorality, bad people and not something to be openly discussed in congregations. Therefore people chose to keep it secret or talk in private conversations particularly regarding matters of HIV/AIDS and modes of transmission.

The Plateau Hospital has attempted to meet the needs of PLWH by means of psychosocial support. The hospital began in 2002, by offering counseling of expectant mothers who were tested and found HIV positive. After two years, a voluntary counseling and testing center was established at the hospital. Prevention of mother to child transmission was established in 2005 and by 2006, educational support to OVC (Orphans and Vulnerable Children) had started. Families of the infected were counseled on how to care for their sick. CBHC also noted that PLWH needed economic stability and they started small income generating activities for families. Plateau has linked up with Moi Teaching and Referral hospital to secure Anti-Retro Viral drugs for PLWH.

The researcher observed during meetings, community visits and consultation with PLWH that even after five years since active CBHC was started, PLWH who received psychosocial support still struggle with spiritual issues which deal with the human quest for meaning and dignity. They face heightened stigma in the community, church and families. Some lose hope and die earlier than expected. Others are rejected in their own homes where, as OVC<sup>9</sup>, they lack a strong support system due to fear that, if people identify with them, they will also be infected with HIV. At the same time, PLWH are seen to be sinners receiving God's just punishment for their immorality. Thus, not many people would want to identify with them (CBHC: 2008)

The researcher is convinced that the spiritual approach to the care and support of PLWH through pastoral care and counseling will offer understanding, unconditional love, compassion, acceptance, affirmation, empathy and God's message of salvation and hope. PLWH need somebody when they ask the God-question. They need somebody to be with them to ensure that their dignity is not compromised even at the hour of death. This will lead to destigmatization and affirmation of human dignity and identity among PLWH.

This approach will ensure that the spiritual, psychological, social, systemic and economic needs of PLWH are attended to holistically. This will not only lead to spiritual healing, but healing of the whole person which will lead to improved life due to the quality of care and support given to

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<sup>9</sup> These are Orphans and vulnerable children who have lost either one or both of their parents through HIV and AIDS and could also be infected.

PLWH in Plateau. Furthermore, through unconditional love, empathetic understanding, and acceptance of PLWH, OVC, and the affected families' compassionate care, instilling of resurrection hope to the hopeless, comfort to the hurting and assurance of God's salvation will be enhanced.

## **1.10 Scope and Methodology**

### **1.10.1 Scope of research**

This paper has concentrated on the care of PLWH in the catchment area of the Plateau Mission Hospital and did not examine the entire intervention of HIV/AIDS in the RCEA.

The reasons for choosing the catchment areas are because that is where the medical approach is applied in the home-based care programme and also because other interventions in the church have varied approaches to care. Since the study focused on Plateau, and not RCEA, the reduction would provide the necessary information. Special attention has been paid to CBHC and the services rendered to communities in the light of the biomedical approaches- with a bias towards integrating spiritual care through the holistic ministry of pastoral care.

This research dealt with four 'support groups'<sup>10</sup> in the four locations of the Plateau Mission Hospital's CBHC catchment area. The study was specific in identifying home-based care support, as implemented by the RCEA's Plateau Mission Hospital. The CBHC programme identified people living with HIV and organized them in support groups according to the areas from where they came. The four support groups are administratively and geographically located in four locations covered by Plateau Mission Hospital.

### **1.10.2 Methodology: Data collection methods, analysis and presentation**

#### **1.10.2.1 Data Collection Methods.**

For the purposes of data collection, the researcher employed a literature review. This entailed a 'review of the existing scholarship or available body of knowledge to see how other scholars

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<sup>10</sup> The four groups comprises of men and women who are living with HIV/AIDS: the women who **have** lost their husband through HIV/AIDS, the men who have lost their wives through HIV/AIDS and community members, mostly women, who are taking care of children who have been orphaned through HIV/AIDS. The groups are found in the four locations covered by the Plateau Hospital catchment area.

have investigated the research problem that the researcher was interested in.<sup>11</sup> The methods included both secondary and primary sources to obtain the relevant data. The researcher used secondary sources as a deliberate consultation and used records from existing works on the area of research. This included reports,<sup>12</sup> books, dissertations, web sources and specific books containing the relevant information in the Reformed church of East Africa.

The research reviewed literature at The Reformed Instituted for Theological Training (RITT) Library and RCEA archived materials in Kenya. Other literature reviews were done at the Stellenbosch University Library, South Africa, NETACT (Network for African Congregational Theology), and the Internet. The necessity of reviewing the existing sources was to provide a framework for the study that the researcher was undertaking.

Primary sources included obtaining data from the District Social Development office, (Statistical office, and Health Department of RSA. The researcher also received data from the Plateau Mission Hospital, and the RCEA. Primary sources provided correct data about the target population. This minimised bias and, furthermore, the data contributed to more insights and forms the basis of Chapters 2 and 4. Information about the target population was obtained through individual and group interviews<sup>13</sup> that the researcher had with CBHC staff, the HIV CBHC Committee, PLWH and congregational leaders (Details of how this was carried out, is discussed in chapter 4).

A quality-structured questionnaire with 14 representative questions was used that covered the

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<sup>11</sup> Mouton J.; 2004: How to succeed in your Master's and Doctoral studies: a South African guide and Resource book: Van Schaik: Pretoria

<sup>12</sup> The reports included Plateau hospital, CARE department and RCEA synod reports

<sup>13</sup> The research also used purposive sampling where the three selected (criteria for selection is shown in Chapter 3 ) groups were studied as representative of the categories in the hospital catchment area. The researcher also did community visits and held community meetings. A few leaders and organizations were chosen for data collection in the area of study. This method of data collection was important since it would help sample eligible participants in the area of study to avoid bias in sampling and hence the data. Having specific categories representing groups of people in the area would also ensure that information is not preconditioned by a status quo or stigma, but truly representative. This would also make people comfortable to release information. Last but not least, empirical research would enable the researcher to gather information that would not otherwise be provided for in the minimal literature review of the few existing documents in the area of study.

hospital activities through CBHC within the catchment areas as follows:

**1.10.2.2. CBHC STAFF/PLWH/CONGREGATION QUESTIONNAIRE**

**Name of Interviewer**-----

**Date**----- **Time**-----

**Respondent** -----

**Role/Religion/Location**-----

**The role of Plateau Hospital CBHC in care to PLWH**

1. How has the staff of the Plateau CBHC programme responded to the HIV pandemic in Plateau?
2. To what extent has the Hospital's HIV/AIDS work impacted on other spiritual issues in te plateau community?
3. How else could CBHC respond to the needs of PLWH?

**How needs of PLWH in Plateau Hospital catchment area are met**

4. How are the needs of PLWH met in the CBHC programme?
5. What needs of PLWH are not met by the hospital support groups?

**Perspectives on pastoral and spiritual care to PLWH**

6. What qualities of pastoral and spiritual care and counselling are needed?
7. What would be expected of pastoral and spiritual caregivers in Plateau?
8. How else could pastoral and spiritual care help in the support of PLWH?

9. Which spiritual resources are used in the CARE of PLWH?

### **Questions on participatory care and support to PLWH in Plateau**

10. What is the level of participation in HIV work?
11. *Who are involved in the pastoral care of PLWH*
12. Who else should be involved in the support of PLWH in Plateau?

### **Issues of stigmatization among PLWH in Plateau**

13. How free are clients to disclose their HIV status?
14. How often do people come for support?

The second method of data collection was by means of participant observation: Here the researcher was involved in the activities pertaining to this study. Using this method, data was collected via participant observation during normal diaconal care activities in the RCEA Plateau parish congregations. This entailed, together with deacons, visiting people living with HIV, taking gifts to children affected by HIV, meeting with volunteer caregivers during visitations, joining the CBHC team during follow-up meetings with PLWH in their homes. The client also consulted patients during voluntary- and counseling (VCT) days and informal meetings with volunteer caregivers. During informal meetings and visits with deacons, the researcher had an opportunity to gain first-hand experience with care giving to PLWH in the field. During the visits, informal group<sup>14</sup> discussions, and informal meetings were important places where data was also collected.

### **1.10.3 Data analysis and presentation**

#### **1.10.3.1 Data Analysis**

Data analysis according to Mouton (2004:108) involves breaking up some of the data into meaningful themes, patterns, trends and relationships. The aim of the analysis is to understand

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<sup>14</sup> The group discussions, interviews and meetings were those selected in the area of study, particularly in the four locations of Kipsinende, Kaptagat, Kipchamo and Chepkero.

the various constitutive elements in one's data through inspection of some the relationships between concepts, constructs, variables, and to see whether there are any patterns or trends that can be identified of isolated or to establish themes in the data.

The researcher also used hermeneutical method to interpret the data with reference to the spiritual realm and people's quest for meaning and dignity.

For data analysis and presentation (Mulwa: 2005:33), the researcher used, tables, charts, and figures to present the findings of the research topic. The researcher also used maps, and sketches to present some specific data collected that helped in the preparation of this report.(Oxford:2005:237,548, 900and 1503)

**1.10.3.2. Tables:** Tables are lists of facts /numbers arranged in a special order usually in rows and columns (Oxford: 2005).

**1.10.3.3 Charts:** This is a page of sheet of information in the form of diagrams lists or figures (Oxford: 2005).

**1.10.3.4 Figures:** Refers to the area of mathematics that deals with adding multiplying etc numbers, or a symbol rather than a word representing one of the numbers between 0-9.

**1.10.3.5. Map(s):** Maps refers to drawing, or plan of the earth surface or part of it, showing countries towns rivers etcetera (Oxford: 2005).

## **1.11. Research design**

In order to collect the relevant data, the researcher had to do library research, pay field visits to the area of study, conduct individual and group interviews, and use participant observation. The researcher also used a purposive sampling<sup>15</sup> method in the four locations in the Hospital's catchment area.

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<sup>15</sup> The researcher used purposive sampling technique as a deliberate way of getting a representative population in the area of study and ensuring unbiased data. This entailed incorporating caregivers, children, women and men

## **1.12. Limitations and delimitation**

### **1.12.1 Limitations**

This study was not able to exhaustively discuss stigma and cultural factors that promote stigma to PLWH in Plateau. The reason for this is not that they were unimportant, but because they are beyond the scope of this research. The researcher was also faced with the challenge of reorganizing meeting groups due to stigma. Traveling was also a problem because the all-weather road, that serves the location of study, is impassable during rainy seasons.

### **1.12.2 Delimitations**

The researcher was able to meet the hospital management and the staff, and communities who offered valuable time and provided important information which helped in achieving the aim of this research.

The study was able to discuss the spiritual care to people living with HIV in Plateau Hospital, in Kenya. The study was able to describe the HIV/AIDS context in Kenya, Uasin Gishu District and Plateau. The study also gave valuable insights on a biomedical approach to health through pastoral care which is viewed as a theological endeavour within the Christian tradition pertaining *cura animarum*. Special reference was made to a pastoral care model through spiritual approach, systematical approach, God-images and the role of the Church in HIV ministry. The study came up with lessons learned and recommendations for strengthening care and support of PLWH and the affected families in RCEA Plateau hospital.

## CHAPTER 2: THE KENYAN SCENARIO: MEDICAL WORK AND THE INVOLVEMENT OF THE CHURCH WITHIN THE COMMUNITY

### 2.1 Introduction

The HIV pandemic has had devastating effects on the Kenyan population and many Kenyans are extremely concerned. Similarly, HIV is a major health risk in the Uasin Gishu district with a prevalence rate of approximately 13.1%. This is twice the rate of the entire Kenyan nation (Uasin Gishu District Strategic Plan 2005-2010:16), which is rated at 6.7%. Find in the Tables below statistics representing the HIV/AIDS figures: National, Uasin Gishu, and in Plateau hospital respectively.

**Table 1: 'HIV/AIDS Kenyan(National) Scenario'<sup>16</sup>**

Indicators	Figures
Estimated number of people living with HIV - 2003	1.2 million
Prevalence rate – adults living with HIV	6.7%
Estimated deaths due to HIV/AIDS as at 2003	150,000
Female percentage of adult population: 2/3 living with HIV	65%
Young women, ages 15 to 24, living with HIV	12.4-18.7%
Young men, ages 15 –25, living with HIV	4.8-7.2%
Estimated number of children living with HIV	650,000
Estimated number of children orphaned through HIV	1.2 million

The research established that Kenya has an average population of 36, 900,000 people. Every year, an increasing number of people are affected by the HIV/AIDS pandemic - either by their own illness, or by that of someone for whom they care. By 2003, over 150,000 people had died. It is estimated that 65% of the women, who form two-thirds of the adult population are living with HIV. The highest numbers of infections are among young people aged between 15 and 24.

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<sup>16</sup> UNAIDS., 2004: UNAIDS country level(Kenya): Global Aids: July 2004.

The young women, between 15 and 24 years, are twice as vulnerable to infection compared to young men of the same age. The national prevalence rate is 6.7%. (NAS COP: 2003). At the moment, Kenya shows a decline in the prevalence of HIV infections, but is still facing a worsening AIDS epidemic with over 1.2 million people infected with HIV, which represents approximately 16% of the adult population. This means that the parents, who died of AIDS, leave behind a large number of orphaned children. Therefore, this large number of AIDS cases in Kenya calls for a particularly urgent rational approach to addressing the problem and its effects. Currently, there are more than one million AIDS orphans in the country, including some suffering from AIDS. ( NAS COP.,2003: National Aids Control Programme: Nairobi).

### **2.1.1 Latest Updates on the HIV/AIDS status in Kenya:**

According to the HIV and AIDS estimates in the Epidemiological Fact sheet as at July 2008, the figures of infections, deaths and prevalence in the Kenyan country seems to be on the increase. It was observed by the researcher that the number of people living with HIV is between 1 600 000 – 1 900 000; adult prevalence rate (between age 15-49) stands between 7.1% -8.3%; women aged 15 and up living with HIV are between 900, 000 – 1, 100 000; children aged 0 -14 living with HIV are between 900 000 – 1,100,000; orphans due to AIDS aged 0-17 range between 1,100 000 – 1,1300 000; adults 15 years and up living with HIV are between 140,0000 – 170,000 and deaths due to AIDS standing at between 90,000 – 110 000. (Epidemological Fact Sheet on HIV and AIDS, July 2008).

## **2.2 The Uasin Gishu District: HIV/AIDS updates**

Uasin Gishu District is one of the Seventeen (17) districts in Rift Valley Province (RVP), with a total area of 3,327.8 km<sup>2</sup>. It extends between longitude 34° 50' and 35 ° 37' east and 0° 03' and 0° 55' north. The district shares common borders with Trans Nzoia district to the north, Marakwet and Keiyo to the east, Koibatek district to the south east, Kericho district to the south, Nandi to the west and Lugari district to the North West. The district is divided into six divisions namely Kapsaret, Ainabkoi, Kesses, Soy, Turbo and Moiben. It is further divided into 35 locations as shown in table 2 below (District Statistics Office, Eldoret, 2001).

**Table 2. Population Densities: Uasin Gishu District**

<b>Table : Area,</b>	<b>Area in</b>	<b>Population<sup>17</sup></b>	<b>Density</b>	<b>Number of Locations</b>
<b>Administrative</b>	km <sup>2</sup>			
<b>Units and</b>				
<b>Population</b>				
<b>Densities Division</b>				
Ainabkoi	473	77,297	163	6
Kesses	692	84,894	123	7
Moiben	778	92,717	119	6
Kapsabet	297	93,162	314	4
Soy	767	165,127	215	7
Turbo	321	109,508	340	5
<b>Total</b>	<b>3, 328</b>	<b>622,705</b>	187.110877	<b>35</b>

Uasin Gishu has a total of 218 health facilities but most of these facilities, particularly hospitals are found in the central division and are therefore concentrated around Eldoret town. The health facilities, especially the public ones, are over utilized due to socio-economic difficulties. Many people cannot afford private hospital charges resulting in over reliance on public facilities. The 3 most prevalent diseases are Malaria, respiratory infections and water borne diseases

HIV/AIDS has become a major threat as prevalence rates are on the general increase and 72% of women surveyed (KDHS:1998) indicated that they are at risk of getting the virus. Uasin Gishu recorded a HIV/AIDS prevalence of 12.1% in year 2001(the numbers may have increased). Both male and female are affected in equal proportions of 1:1

(District Medical Officer of Health (DMOH) as quoted in the Uasin Gishu District Strategic Plan 2005-2010p. 9)

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<sup>17</sup> The projected population for Uasin Gishu District as at 2008 is 794322

**Figure Table 3: Uasin Gishu District: HIV/AIDS scenario**

Indicators	Figures
Population – 1999 Census	622,705
For every 1000 births	39 infected with HIV
Annually	100,000 born with HIV
Prevalence rate	13%

According to NASCOP estimates, the HIV prevalence rates in Uasin Gishu stood at 13%, which is twice the rate of the national adult infection. For every 1000 births, HIV (that causes AIDS) has infected 39 infants. The records also revealed that 100,000 infants are born HIV positive every year, hence the increase in the infant mortality rate (IMR). The reports added that, in 1998, there was an increase in the IRM due to HIV infections. The child transmission route was either through breastfeeding or during pregnancy, and around the time of delivery (NASCOP.2003. National AIDS Control Programme as quoted by the Plateau Mission Report of 2003).

### **2.3 Background Information: Reformed Church Of East Africa (RCEA)<sup>18</sup>**

In the RITT library, the researcher researched written works in the form of reports, books and archive materials on community-based care in the Plateau Mission Hospital and the history of the RCEA. The study gathered the following data in the literature review:

#### **2.3.1 The Reformed Church of East Africa Organizational Structure<sup>19</sup>**

The Synod is the highest office of the RCEA. The Synod<sup>20</sup> office comprises 280<sup>21</sup> delegates from its 450 congregations. Under the Synod Office is the Executive Committee, which comprises the Synod Moderator, the General Secretary, the Honorary Treasurer, the Deputy General Secretary, the Deputy Moderator, and 14 members from the four presbyteries, among whom are

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<sup>18</sup> Van Zyl, J. 2001. The impact of Reformed missions on the origin, growth and identity of the RCEA (1500-2000. Dissertation; pp 41-114, Eldoret.

<sup>19</sup> Refer to Appendix 2 – The organizational structure of the RCEA.

<sup>20</sup> Representatives to the synod court are 51 delegates

<sup>21</sup> The four RCEA presbyteries have a total of 70 delegates per presbytery .

representatives from the deacons' office, the representative of evangelists, the representative of theological education and the Chairman of the Finance Committee.

Under the Executive Committee we have four office bearers with the synod Moderator, General Secretary, Deputy Moderator, and the Deputy General Secretary. The Moderator is the official representative of the church and the spiritual leader. Local churches, parishes and presbyteries are answerable to him, whereas the General Secretary is the executing officer of Synod resolutions. All projects, programmes and departments and their representative committees are answerable to him. In the event that the Moderator and General Secretary not being in the office, the Deputy Moderator and Deputy General Secretary carry out their official responsibilities. The Honorary Treasurer, the Finance Committee and the Accounts Office oversee all financial matters,<sup>22</sup> program proposals and reviews.

### **2.3.2 Establishment of the Reformed church of East Africa (RCEA).**

The RCEA<sup>23</sup> was established as a result of the Reformed missionary enterprises of the Dutch Reformed Church (DRC)<sup>24</sup> and the Reformed Mission League (RML). The DRC established congregations among South African white settlers who had arrived in Kenya as from 1905. Later, the Church spread<sup>25</sup> first to African labourers and later to Uasin Gishu and Kitale by means of spontaneous outreach mission towards the local people. The RCEA was formally instituted in 1963 and had congregations in Plateau, the Eldoret town and Kitale.

### **2.3.4 Medical work of RCEA**

Mrs. Eybers pioneered the RCEA's medical work. This led to the building of a medical clinic at the Plateau Mission Station. The medical services, as diaconal work, was provided free of charge to the locals (Vergenoeg LMC 04/01/46 & Eybers 1949, as quoted by Van Zyl 2001:96). Medical

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<sup>22</sup> Annual budgets, proposals, financial accounting, financial reports, reviews, monitoring and evaluation.

<sup>23</sup> The above structure shows the leadership of the RCEA. The highest court in the Synod office chaired by the Synod Moderator.

<sup>24</sup> Van Zyl, J. 2001. The impact of Reformed Missions on the origin, growth and identity of the RCEA. (1500-2000). Dissertation, pp 41-114. Eldoret.

work, as health instruction, was one of the areas covered in the initial mission policy of the DRC (Cronje 1981:125, as quoted by Van Zyl 2001). Mrs. Eybers's concern about the mission clinic, together with her encouragement, led to the building of a nurses' home for the medical personnel (Van Zyl: 2001).

From the time it was established, RCEA Plateau hospital renders her services to the community; outpatients, laboratory, maternal and child health, inpatients in medical wards, and maternity. The most common diseases reported are malaria, respiratory tract infections, diarrhea and HIV/AIDS. The hospital has 80 beds (Medical department Annual Report To RCEA Synod: 2000).

By 1999, the RCEA's medical work had expanded to include West Pokot, Turkana, Trans Nzoia, Uasin Gishu, Nandi and Keiyo. Health services were offered in the following health units:

**Table 4: The RCEA health units for medical work**

Number	Name of Facility	Location
1	Plateau Mission Hospital	Plateau
2	Ainabkoi dispensary	Ainabkoi
3	Kipsaos dispensary	Kipsaos
4	Lessos dispensary	Lessos
5	Tugen Estate dispensary	Moiben
6	Ndalat health centre	Ndalat
7	Lokichar health centre	Lokichar
8	West Pokot health centre	Marich
9	Kocholwa health centre	Kocholwa
10	Maridadi dispensary	Kitale

These units offered curative care at clinical level and maternal and child health (MCH) services at the facilities mentioned above, or at mobile clinics in the target communities. Both stationary and mobile clinics provided preventive medicine.

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<sup>25</sup> Interview; October 2007; Rtd Moderator Rev. Joshua Biboko, first Moderator of the RCEA: Eldoret

## 2.4 Location of Study

The area of research for this study was the Plateau Hospital's catchment area in the Kipsinende location, Ainabkoi Division, Uasin Gishu District in the Rift Valley Province. The Plateau Mission Hospital is one of the oldest locations of the RCEA's Medical Department. In 1954, it started as a small dispensary and grew to an 89-bed hospital with satellite clinics scattered around it. The distance of these clinics vary from 20 to 60 km from the Plateau hospital, which is situated 25 km south east of the town of Eldoret. All-weather roads that are impassable during the rainy season serve the hospital. Its CBHC programme is situated at the Plateau Mission Hospital. This study focused on the HIV/AIDS project in the hospital's catchment area in the four locations of Kipsinende, Kipchamo, Chepkero and Kaptagat that are covered by the CBHC project. The following tables display the statistical data for each area, and the initial HIV sero-positive data:

**Table 5<sup>26</sup>: Statistics for Plateau Hospital's catchment area**

<b>AREA</b>	<b>MALE</b>	<b>FEMALE</b>	<b>TOTAL</b>	<b>HOUSE- HOLDS</b>	<b>AREA</b>	<b>DENSITY</b>
Kaptagat	3997	3932	7929	1354	67.3	118
Chepkero	3151	3358	6509	1245	42.9	152
Kipchamo	3182	3050	6232	1230	74.1	84
Kipsinende	2904	2730	5434	1076	54.6	103
Plateau	2384	2467	4851	871	26.1	186

**Table 6: CBHC Initial Ante-natal (ANC)<sup>27</sup>/HIV Data**

ANC & IN-PATIENTS/HBC	YEAR	HIV CASES
MOTHERS ANC CLINIC 18%	1999	positive status
MOTHERS 62	2000	positive status
IN-PATIENTS 45	2003	positive status
CBHC 75	2008	positive status
OVC 200	2008	Educational support

The above figures for those people that are infected and affected may vary from the actual number of those who are infected in Plateau. This is because stigma discouraged people to openly disclose their HIV status, leave alone to go for voluntary counseling and testing at the VCT center at Plateau hospital. The numbers only indicate those targeted by the CBHC programme, and those who have been identified or have disclosed their status.

#### 2.4.1 Organization and Structure: RCEA Plateau CBHC programme

The CBHC<sup>28</sup> is one of the departments of the Plateau Mission Hospital. The administration of the Hospital is in charge of this department and a co-ordinator, a medically trained and qualified community health nurse, heads the department. The hospital's steering committee<sup>29</sup> and the administration<sup>30</sup> supervise the co-ordinator and her team. Due to the unique roles of the co-ordinator, as the financial administrator and over-all head of the department, she works jointly with the financial office and quality assurance through requisitions, receipts, bank accounts and payment vouchers.

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<sup>26</sup> CBHC: 2002. CBHC – HIV/AIDS progress report: 4th quarter: Plateau p.4.

<sup>27</sup> Anti-Natal Clinic at the MCH department of the Plateau Mission Hospital shown in the CBHC: 2003: CBHC – HIV/AIDS progress report: 4th quarter: Plateau p.7.

<sup>28</sup> CBHC Report: June 2008: CBHC; Plateau.

<sup>29</sup> The steering committee also assists the project in the strategic planning and project review process, holding the CBHC accountable, and helps in mobilizing for PLWH and OVC. The steering committee also provides leadership to the project, offers management and carries the vision of the CBHC.

<sup>30</sup> The hospital administration is in charge of working with the CBHC staff on policy, administration and financial accounting matters.

On implementation of project activities,<sup>31</sup> the co-ordinator works with volunteer community health nurses from the Plateau hospital, trained trainers on community-based health care, community and church volunteer caregivers, a theologically-trained chaplain, community- and church leaders, and families who take care of orphans and child heads of households.

The CBHC collaborates with local ARV therapy clinics managed by AMPATH, (academic model for prevention and treatment of HIV), particularly for ARV and opportunistic infections (OI) treatment; community leaders, religious leaders, the children's department for the protection of children and household rights and properties, and the RCEA care department for the mobilization of the church's congregations for the care and support of OVC and PLWH.

The CBHC's main objectives<sup>32</sup> are the strengthening of 75 caregivers affected by HIV and also meeting their basic needs, reducing physical and emotional suffering of 75 PLWH, and increasing the care and support of 200 OVC by means of school fees and basic necessities.

The main activities of the CBHC are assessing caregivers' individual needs, households, PLWH, and OVC.

Beneficiaries<sup>33</sup> of the CBHC, in groups within the catchment areas, are the OVC, PLWH, caretakers of orphans and affected families. The CBHC offers basic training on HIV/AIDS home-based care and care for the OVC; provides agricultural input to increase the nutritional capacity of affected and infected households; provides initial assistance for income-generating activities for carers to enable them to provide for themselves and for the people for whom they care, the PLWH and OVC; provides nutrition and livelihood support; increases the OVC's access to education by the provision of fees, uniforms, and vocational training; they also link PLWH and OVC to legal entities for the provision of legal support for the protection of property and planning the affected families' future; and link the PLWH with health care facilities to provide

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<sup>31</sup> CBHC Report: June 2008: CBHC; Plateau.

<sup>32</sup> Ibid.

<sup>33</sup> Ibid.

access to ARV- and OI treatment. Finally, the CBHC provides psycho-social support and continuous counseling.

## **2.4.2 RCEA Plateau Hospital Community-Based Health Care**

### **2.4.2.1 Background information**

In January 2002, a project on HIV/AIDS that focuses on home-based care was started in the Plateau Mission Hospital due to three main reasons:

1. An increase in the incidence of HIV/AIDS in the hospital's catchment area
2. The realization that the disease was highly stigmatized in the area
3. The fact that very few of the AIDS patients admitted at the hospital died at the hospital, which indicated a need for home-based care.

Records from the Plateau Mission Hospital ANC department of 1999 indicated that 18% of the mothers who attended the clinic were HIV positive. Other records showed that, of the new admissions in the hospital in 2000, 62 people tested positive for HIV; 45 cases admitted had previously been admitted, of which three had died in the hospital.

As most of those who died of Aids were parents, it was evident that there were many orphans and their care was a rising problem that needed attention. In the community at Plateau, there was an outcry that was expressed mainly during community meetings. Moreover, there were children who were born with the HIV virus and they too needed care and support (Plateau: Mission Hospital CBHC Report 2003:8).

Care for the orphans and women who are traditionally the caretakers seemed particularly important. On the one hand, the increasing numbers of innocent children orphaned through HIV needed help to grow up into responsible citizens. On the other hand, women were the most stigmatised and yet the CBHC observed that women's roles were quite central in the care for the sick in most Kalenjin<sup>34</sup> families in Uasin Gishu.

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<sup>34</sup> Should it happen that a member of the families in the Kalenjin community (where the researcher comes from) are unwell, their communities traditionally expect both the young women, the elderly and young girls to nurse the sick.

The mother-to-child route is the main mode of HIV transmission to children. Mother-to-child transmission occurs during pregnancy, during delivery and during breast-feeding. The risk factors include:

- placental infections,
- a high viral load,
- a prolonged rupture of amniotic membranes,
- invasive delivery techniques , e.g. episiotomy,
- the mother's nutritional status,
- the pattern and duration of breast-feeding and the health of her breasts.

The project's aims were:

1. Reducing the prevalence of HIV in the hospital's catchment area;
2. Improving the comfort of people living with AIDS,
3. Prolonging the life-span of people living with AIDS.

The project activities of CBHC included:

1. Training of counselors at the hospital
2. Home-based care visits
3. Voluntary counseling and testing (VCT)
4. Continuation of resource centre work
5. Mobilizing communities for prevention-of-mother-to-child-transmission (PMTCT) meetings
6. The follow-up of women with sero-positive status
7. Identification and care of orphans
8. Training of village volunteer caregivers in the community
9. Establishing a VCT centre at the hospital
10. Beginning home-based care activities in the catchment area
11. Follow-up VVCs, TBA and CHW

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The custom is also that, whenever women become ill, the women who are well are expected to nurse their fellow women. Men hardly ever nurse the sick members of the family.

## 12. Medical care of orphans and those infected.

By November 2002, the AIDS project of the CBHC was in its last phase, that is active home-based care and follow-up of the village volunteer caregivers (VVC) who were trained to do the work. Indicators of success drawn up when the project started were used to monitor and evaluate the project's activities. Reports on how the project's progress measures up to the indicators were rewritten quarterly. From 2003 to date, CBHC has been offering OVC and PMTCT a resource centre, referrals, ARV drugs, and home-based care services in Kipsinende, Kipchamo, Plateau and Chepkero sub-locations in the Ainabkoi division (CBHC Report: 2007). The CBHC project goals were:

1. To prevent mother-to-child transmission of HIV and contribute to the overall improvement of the general status of life of AIDS orphans in Plateau by providing them with holistic care as a base for a brighter future.
2. The continuation of the project's first phase, i.e. home-based care and VCT.

### **2.4.2.2 The main objectives of the CBHC Programme**

1. To create awareness on the recently introduced PMTCT of HIV to newborn children.
2. To monitor the progress of HIV positive ante-natal women and follow up HIV positive women who visit the Hospital's antenatal clinic.
3. To reduce physical and emotional suffering of AIDS patients.

From 2002, the Plateau Mission Hospital has served people living with AIDS as well as OVC. The community-based health outreach links HIV positive OVC and caregivers to clinics run by the Moi Teaching and Referral Hospital in the Uasin Gishu district for ARVs and treatment for OI, such as tuberculosis (TB). The training of volunteers, counsellors, and church leaders enhances HIV/AIDS awareness in communities.

1. The RCEA has established both a PMTCT program and an HIV/AIDS resource centre, and has also developed an education curriculum for primary schools sponsored by the church.

## **2.5 Services offered by CBHC to the Plateau community: Summary**

### **2.5.1 The VCT project**

The Plateau Mission Hospital's home-based care department administers the VCT services, which are offered free of charge to people who willingly visit the health facility and want to know their HIV status. Expectant mothers are also sent to the centre in order to determine their HIV status so that, if found HIV positive, they can benefit from the PMTCT arrangement in the Hospital.

Trained and qualified counselors offer the VCT services. After pre-test counseling, the clients are tested and, upon receipt of the results, the clients are again counseled (post-test counseling). This helps the clients to understand how to live positively if found that they are HIV/AIDS infected and, if not, to be careful to remain uninfected.

The CHBC staff take the VCT services to communities during visits, and clients, who cannot visit the hospital but are willing, are then tested and counseled and, if need be, referred to the Moi Teaching and Referral Hospital's AMPATH department.

### **2.5.2 The prevention of mother-to-child transmission (PMTCT)**

The PMTCT of HIV is the Hospital's service where expectant and lactating<sup>35</sup> mothers infected with HIV receive medical care in a bid to prevent infecting their unborn babies.

### **2.5.3 The Resource Centre facility**

The Plateau Mission Hospital's Resource Centre is situated within the HBC office in the Plateau Hospital. The Resource Centre offers literature on HIV and HIV-related topics, reports and

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<sup>35</sup> After delivery, mothers are discouraged from breastfeeding their children. This is aimed at minimizing the HIV infection from the infected mother to the uninfected child. Mothers are advised to feed babies with supplements

brochures. Also available in the Centre are audio-visual video tapes containing facts about AIDS, the care and support of PLWA, OVC<sup>36</sup> care and support, and care and support of widows/widowers. VCT clients waiting for attention have a chance to watch the TV shows, and read the literature (Julia: interview, Nov 2007, Eldoret). People come to the Centre for VCT, for follow-ups and community contacts (CBHC 2003-Quarter 4: Progress report: Plateau).

The CBHC has established a resource centre at the Plateau Mission Hospital. The Resource Centre supplies videos and literature on HIV/AIDS management. Clients, who come for voluntary counseling and testing and follow-ups, can read this literature and watch these videos. The CBHC staff also uses the television and video machines for community education and sensitization (Esther: Sept 2007, Plateau).

#### **2.5.4 The active home-based health care**

Active home-based care (HBC) is rendered in the Hospital's catchment area. The CBHC coordinator organizes this. The coordinator, the nursing staff, counselors, and village and Christian caretakers cooperate with the communities to visit, cook, clean, and spend time with HIV/AIDS clients.. The HBC has a programme on a specific day when the officer visits the clients, but the caretakers visit them quite often. The main purpose is to talk with the clients, promote the nutritional support to PLWA, encourage them to take the medication and referral, if need be. During the visits, the clients are also encouraged to live positively: eat, exercise, avoid re-infection, and to avoid foodstuffs that will weaken their health (Esther: interview, Nov. 2007, Eldoret).

#### **2.5.5 The Referral Services - AMPATH Moi Teaching and Referral Hospital (MTRH)**

The Plateau Mission Hospital's administration and CBHC coordinator offers referral services to the MTRH in Eldoret and ARV and opportunistic infections centres run by the MTRH's AMPATH program, in the Uasin Gishu District. At these centres, they receive their ARV

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including animal milk products, porridge and fruits.

<sup>36</sup> Dixon, P. 2002. AIDS and you. Acet International: London, p. 130.

treatment, counseling, support and check-ups. Some clients are sent to the MTRH for further medical consultation and treatment of severe OI's, such as TB and skin cancer (Esther: interview, Nov. 2007, Eldoret).

### **2.5.6 The OVC project**

The OVC's care project targets children whose parents both have died and those with one surviving parent. These children could be living with the HIV virus or be at risk as a result of losing their single parents, the sole breadwinners. Through the CBHC programme, these identified orphans are supported with partial school fees, guidance and counseling, school uniforms and food supplements (Esther: interview, Oct 2007, Eldoret).

### **2.5.7 Nutritional programme**

The nutritional program of the RCEA's CBHC project in the Plateau Hospital supports sick people and vulnerable children with nutritional supplements. The Hospital gives the clients mainly amaranth flour for making porridge, ugali (mealie meal pap) and cookies rich in vitamins, minerals, proteins, fibre, and carbohydrates. The program has enabled clients who suffer from malnutrition to receive food supplements even when food is scarce.

### **2.5.8 Hospital chaplaincy**

Plateau Hospital has a chaplaincy structure. The chaplaincy ministry has one theologically-trained staff. The duties and responsibilities of the chaplain is to give spiritual encouragement to out- patients, in-patients in wards, both the support and non-subordinate staff. The chaplain also gives spiritual guidance to the girls in the RCEA Plateau Girls High School, and RCEA Plateau primary school children.

The researcher observed during visits to Plateau Hospital that the medical approach treats this chaplaincy ministry as secondary for instance medical staff give minimal support towards strengthening the ministry. Also, the ministry demands are more that the deployed staff since the hospital has only one fulltime chaplain in charge of chaplaincy ministry. The Services offered by

the chaplain are also limited to opening and closing prayers. The spiritual needs of the PLWH who come to the Hospital and those in communities<sup>37</sup> require quality time, more than one person, and change of approach. The medical staff also needs to do referrals to the chaplaincy for follow up and care in the communities. The hospital also needs to build a team (among the volunteer care givers in the field) around the chaplaincy to ensure appropriate spiritual care to PLWH is given.

## **2.6 The CBHC'S HIV/AIDS Needs and services assessment**

### **2.6.1 Introduction**

Providers of care (nurses and volunteer caregivers) to PLWH at the Plateau Hospital have embraced mainstream biomedical approaches<sup>38</sup> to manage HIV. From the beginning of the CBHC programme at the Hospital, this institution regarded the biomedical approach as “effective care”<sup>39</sup> to PLWH and, no other methods, including spiritual care, were considered to be effective in improving the patients’ health.

The Hospital’s medical culture influenced disclosure related to prognosis and diagnosis, and the role of patients (PLWH) and families in decision-making. Nurses, clinical officers and doctors, with biomedical orientation, have shaped clinical work to impact on medical therapy by educating caregivers, patients, families and communities on medical procedures and practices.

The most pronounced diagnostic work in the Plateau Hospital included prevention and treatment of disease, VCT, ARV, MCH and PHC, amongst others.

Therefore, the biomedical model provided the Hospital with the cultural environment in which physicians and non-physician caregivers carried out work<sup>40</sup> in the Hospital and in communities

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<sup>37</sup> Within the communities, PLWH in the home-based care programme feel that spiritual care and support should also be extended to them, their affected families, and the OVC who cannot visit the Hospital (interview: PLWH group. July 5, 2008. Plateau).

<sup>38</sup> The nursing team and those trained by the nursing staff (volunteer caregivers in the community and church-based caregivers follow true biomedical approaches to care and support of PLWH, orphans, affected families and widows.

<sup>39</sup> Improvement of the overall health of PLWH in the Plateau Hospital.

<sup>40</sup> The CBHC staff gives PLWH: treatment of opportunistic diseases, home-based care and support of PLWH,

within the Hospital's catchment area. The Hospital offers curative and preventive services by means of voluntary counseling and testing (VCT), primary health care (PHC), maternal child and health (MCH), home-based care (HBC), education-sensitization in communities through community public meetings, group meetings and follow-up visits. Medically trained and qualified nurses, clinical officers and medical doctors spearhead all of these. In the CBCH programme, the coordinator, a trained community nurse, organizes the care and support of PLWH according to the Plateau Hospital's requirements. Below are the CBHC services run by the Hospital:

**Table7. CBHC services in order of priority**

NO.	CBHC services	Percentage
1	HIVAIDS Awareness & prevention	45%
2	Voluntary Counseling & Testing & PMTCT	25%
3	Home based care	10%
4	Orphans and Vulnerable Children care and Support	10%
5	Income Generating Activities	7%
6	Nutritional supplements	3%

As shown in the Table 7 above, the researcher established that CBHC's area of priority is creation of HIV awareness in the hospital catchment area. The researcher established that the staff does this through open community meetings, through literature at the resource center and HIV Video shows in the community. Number two in order of priority is voluntary counseling and testing done at the VCT center in Plateau and sometimes in communities after awareness meetings. Follow up for treatment counseling and community care for the terminal clients in the four support groups is third, followed by educational support for orphans and Vulnerable children (OVC). Economic empowerment of PLWH through loans for small and manageable businesses is fifth. Finally, Nutritional support with amaranth flour for porridge for PLWH and OVC's is still an area that has not grown. Below are some areas the CBHC team identified that need to be addressed in order to serve PLWH well.

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support of people affected by HIV, voluntary counseling and testing, and decision-making.

During consultative meetings with CBHC<sup>41</sup>, the following were expressed as key areas that need to be looked at in order to improve the quality<sup>42</sup> of life and reduce suffering to PLWH, the affected families, and communities in Plateau:

- Fighting stigma in the community, including churches
- God's love, mercy and grace must be shown by his people/servants
- The experience of church members' attitudes that HIV/AIDS is God's punishment increases the stigma
- Fear of eternal life (what will become of them after death?) of all human beings, as per the Word of God
- Poor food security: this needs education, training and assistance concerning other kinds of food that are easily cultivated
- Due to opportunistic infections, the People living with HIV/AIDS (PLWH) cannot pay their bills for treatment in the Hospital. This challenges their lives and reduces their lifespan.
- Training the PLWH on the need for writing a will in order to protect their property and assets and prepare for their children's future.
- Training church/community leaders and volunteers in the care of OVC and PLWH. Reducing stigma and discrimination within the society towards PLWH.
- Mobilization and teaching PLWH and the entire community on:
  - ✓ The importance of care services,
  - ✓ HIV/AIDS information, including modes of transmission and prevention,
  - ✓ Care of OVC and PLWH.

## 2.7 Concluding Remarks

In chapter two, the researcher discussed the Kenyan Scenario: Medical work and the

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<sup>41</sup> CBHC 2008: CBHC July Brief report: CBHC: Plateau.

<sup>42</sup> The Coordinator of the CBHC said categorically that, apart from the medical and psychosocial support, acceptance, love, care, and understanding that could be offered through the spiritual model, caregivers could enable the facility to offer quality care to all who come to the hospital and those cared for in homes. In her view, this will reduce the stigma (*ibid.* 2008).

involvement of the church within the community. The study attempted to answer the questions: How has the staff of the Plateau/CBHC programme responded to the HIV pandemic in Plateau? Who are involved in the pastoral care of people living with the CBHC? How are the needs of PLWH met in the CBHC programme? What needs of the PLWH are not met in the Hospital's support groups?

This chapter established that, in response to the needs of PLWH, the Plateau Hospital uses a psycho-social model to meet some of the needs through: OVC, home-based care (HBC), PMTCT, referral for OI treatment, ARV and nutritional support. The researcher also found that the people involved in the care and support of PLWH and their affected families are the medically trained coordinator, volunteer nurses, and caregivers who have received training at the Hospital.

Upon examination of the broader HIV picture, the researcher established that the pandemic is still a major concern in Kenya. This country has a prevalence rate of 6.7%, just under the overall sub-Saharan percentage of 7.5%. It is estimated that over 1.2 million Kenyans are living with HIV infection, 1.2 million children have been orphaned through HIV, and approximately 650,000 children are living with HIV. This study also established that, at district level, the effect of the pandemic is even more serious. The prevalence rate at Uasin Gishu is 13% - twice the national infection rate among adults. And in the district, Ainabkoi division from where Plateau is situated geographically and administratively, the impact is even higher. The other reasons for the HIV challenge in Plateau are similar to the challenges elsewhere in Uasin Gishu district<sup>43</sup>, viz. slow behavioural change, strong cultural beliefs and low motivation among those active in the HIV care ministry.

The challenge of HIV at Plateau as mentioned in the preceding section motivated the researcher to do a pastoral assessment at RCEA Plateau Mission through field study. The findings are given in the description in the following chapter.

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<sup>43</sup> National Coordination agency for population and development: 2005: 2005-2010 strategic plan for Uasin Gishu. Nairobi, p.19.

## **CHAPTER 3: A PASTORAL ASSESSMENT AND FIELD DESCRIPTION OF THE RCEA PLATEAU MISSION HOSPITAL.**

### **3.1 Introduction**

In the previous chapter, it has been established that HIV/AIDS has impacted Kenyan communities drastically. The research showed that in the RCEA medical response to the HIV pandemic, Plateau Mission Hospital was involved in Plateau community through her community based health care programme. An attempt will be made to provide an in depth study of RCEA Plateau mission hospital -through a pastoral assessment and description.

The flow of presentation in this chapter is as follows: Section 3.1 is an introduction to the entire chapter. Section 3.2 focuses on the research preliminaries. This entailed identification of the area of study, determination of the target<sup>44</sup> population and criteria for selection. Also important was formulation of the set of questions (questionnaire)used in the interviews . Section 3.3 attention is on the analysis and presentation of RCEA Plateau Mission Hospital data. This included the respondents' feedback on the set of questions used in the individual and group interviews. Section 3.4 is mainly the evaluation on the collected data. A conclusion to the chapter will then follow in section 3.5.

The following are the findings of the interviews conducted in the RCEA Plateau Mission Hospital. The interviews targeted men, women and children infected and affected by HIV. The targeted interviewees comprised caretakers of the CBHC programme, officials in the HIV/CBHC management committee, and the congregations - the community where HIV is experienced. All responses were recorded, analysed, evaluated and presented in a narrative way.

The following preparations were made prior to undertaking the research process: The researcher participated in some studies that were done in 2007, by the RCEA's HIV/AIDS programmes,

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<sup>44</sup> The total target group comprised 20 respondents. For proper management, the study limited this target group and also considered the fact that the group be representative enough.

HIV/AIDS fundraising workshops and diaconal ministry implementation. More focused interviews were conducted between the end of 2007 and mid-2008.

### **3.2 Research Preliminaries**

The researcher began by establishing the goal of the research. This was to determine from the staff members, committee members, PLWH and families affected with HIV how the CBHC at the Plateau Hospital has responded to the spiritual care and support of people affected and living with HIV, and to determine what spiritual needs had not been addressed. The researcher embarked on discovering who is involved in the care, what else pastoral care can contribute, by means of a spiritual model, to bring about holistic healing of the infected, affected people, and communities supported by the Plateau Hospital by means of the CBHC programme.

The researcher also embarked on identifying the area of study, i.e. the Plateau Mission Hospital's Community-based Health Care programme. This is a health facility of the RCEA. The location covered the Plateau Hospital HIV care activities in the Hospital catchment areas of Kipsinende, Kipchamo, Kaptagat and Plateau locations, in Ainabkoi division, Uasin Gishu district, Rift valley Province in Kenya.

A sample was determined by targeting caregivers, the CBHC staff and committee, PLWH, and congregations/communities from which PLWH came. The methodology used was interviews that the researcher conducted through participant observation, as coordinator of the diaconal ministry in RCEA collaborative work with the CBHC on acts of mercy (diaconal visits), one-on-one and group interviews.

A set of questions covering the research question areas was designed to form the questionnaire that was used as a guide in the interviews that the researcher conducted. Interviews were conducted by visiting PLWH in their homes, meeting the CBHC staff and committee in their office and joining them in follow-up visits with a home-based care programme, and participating in the work of deacons (acts of mercy). In the process data was collected.

The collected data was analysed and presented as Chapter 3 in this study. This served as a way of enabling the researcher to present what the Plateau Hospital is doing in terms of care to meet the

unmet spiritual need amid the dominance of the biomedical approach in the care of PLWH. This also helped to identify some of the needy areas, and also what pastoral care, through a spiritual approach, can do to help realize holistic healing, to result in a reduction of the HIV stigma in Plateau.

As we see in the table below, the researcher made preparations for the field research. The researcher determined the criteria for selection of the interviewees, and worked with CBHC staff and volunteer caregivers to get a representative target population. Things that the researcher considered were; gender, category<sup>45</sup>, level of education, relationship, and age as we find in Table 8 below.

**3.2.1 Table 8: The RCEA’s Plateau Mission Hospital, Kenya: Interview plan**

Nature of groups of Interviewees <sup>46</sup>	PLWH	CBHC staff	Congregation
Gender	Male and female	Female and male	Male and female
Age	<ul style="list-style-type: none"> <li>● Children</li> <li>● 25 – 35</li> <li>● 40 – 55</li> </ul>	25-45 Female only between the ages above	35-55 Both male and female between these ages
Education	Understand and speak the national language	Understand and speak English/national language	Understand and speak National language/experience/English
Nature of groups of Interviewees	PLWH	CBHC staff	Congregation
Relationship	Infected/affected This was aimed at getting true reflections of the experience of PLWH.	Affected/caregivers Aimed at getting information from the affected family members and caregivers of affected members - people who	Infected/affected/caregivers People themselves infected, others having infected relatives of orphans and widows,

<sup>45</sup> This entailed the caring teams (CBHC Staff and committee and the Congregation), the People living with HIV/AIDS.

<sup>46</sup> The researcher set the criteria for the people to be interviewed (target population), and then worked with the CBHC Coordinator to get the children, men, women, caregivers and the affected families served by CBHC for both group and individual interviews.

		have witnessed experiences of PLWH/ affected.	and those involved in caregiving for the PLWH.
Setting/how	Individuals Individuals were approached as no group interview could be held. There is still a lot of stigma and PLWH choose to keep their status secret.	Staff/CBHC committee Coordinator, field staff, volunteer caregivers, volunteer nurses, all CBHC committee and Hospital members.	Group This was a group of leaders in the church: pastor, parish council members, deacons, elders, women leaders.
Numbers involved	10 2 Children 4 Men 4 Women	5 3 Staff members 2 Committee members	5 1 Chairperson 1 Secretary 1 Deacon 1 Female leader 1 Minister
Where	In group areas: Plateau Kipsinende Kipchamo Kaptagat Plateau The interviews were held in homes of the PLWH because of the stigma.	At the Hospital's CBHC The interviews were held in the Hospital CBHC office, a central place where the staff and the committee meet.	Parish Headquarters The interviews were held in the parish headquarters where the parish council and the congregation leaders have meetings.
Referral	The field officer referred the PLWH to the coordinator and to me. First person chain referral.	All information was received from the staff at the CBHC since they are the implementing personnel in the Hospital.	The pastor referred me to the deacons, who referred me to caregivers. Third person chain referral
Method of questioning	Oral/individual	Chorus/group	Chorus/group

NOTE: Here are notes for the above interview implantation plan:

**1. Age:**

1. PLWH: This was aimed at covering all age groups of all people infected with HIV.
2. Female, The CBHC: This tool took into consideration the long serving staff at the CBHC and those who had just joined the congregation, but still young in terms of age.
3. Male and female members of the congregation: They included the serving-age group in the congregations: elders, deacons, council members, and ministers.

**2. Mode of questioning:**

- The research employed personal one-on-one interviews, particularly with the PLWH: men women and children, as it was impossible to meet as a group. People fear stigma and respondents felt more comfortable responding to questions as individuals in their own homes.
- Both the committee and the staff members were free in responding to both individual and group interviews that the researcher conducted.
- The congregation had no problem having a group interview conducted by the researcher

**3. Numbers involved - Target population:**

1. The interviewer targeted 20 respondents. Of these, three categories were considered. The first category comprised PLWH, in which group were children, men and women all living with HIV. Two were children, four were men, and four were women.
2. The second category comprised the staff working with the CBHC and members of the CBHC HIV/AIDS management committee. Five respondents were in this category: three female staff members and two male committee members.
3. The third category of respondents was a total number of five who represented members of the congregation, two women and three men: the minister of the congregation; two women (one representing the women's office and one representing the deacon's office); and two men from the parish council.

**4. Referral**

- The researcher had a chain referral in the search for required data. She had contact with the programme coordinator who referred her to specific PLWH for individual information

and some of them, in turn, referred her to other PLWH (children) whom they felt had more relevant information with regard to children's experience.

In the following table let us look at the set of questions used by the researcher and the responses<sup>47</sup> given by community based Health Care Staff and committee, the congregation and the people living with and affected by HIV and AIDS in Plateau.

**3.2.2 Table 9: The RCEA Plateau Hospital's interview responses**

Question Number	Group 1 PLWH	Group 2 CBHC Staff	Group 3 Congregation
1 How has the CBHC programme/ staff responded to the HIV pandemic in Plateau?	Visitation Medicine Food Fees VCT	Visitation Medicine Food Fees VCT Linking (networking) HIV awareness creation	Visitation Medicine Food
2 Who are involved in the pastoral care of people living with HIV?	Coordinator Nurses Volunteers	Coordinator Nurses Volunteers	Deacons
3 How are the needs of PLWH met in the CBHC programme?	Hospital VCT ARV Visitation OVC	Hospital VCT OVC Visitation	Deacons Visitation
4 What needs of the PLWH are not met by the Hospital support groups?	Love People hate PLWH and the affected families.	Need God's love, mercy and grace. Negative attitudes HIV/AIDS is a	Fear Fear of coming closer - can be infected. Love

<sup>47</sup> The responses were both individual (from people living with HIV/AIDS and the affected families such as the orphans and vulnerable children), and group responses especially from the congregation, CBHC staff and the HIV and AIDS(CBHC) management committee members. The interviewees are in groups for instance Group 1 for PLWH, group 2 for CBHC staff and Group 3 Congregation.

Care	punishment.	Some people hate PLWH.
Nobody cares about the PLWH apart from the Hospital staff.	Increased stigma	Rejection
Anger	Fear of life after death.	Families force them out.
PLWH, and OVC are angry with themselves, God, family and friends due to their illness.	Some are not sure of what will happen to them.	Attitude: punishment
Guilt	Respect	Some say PLWH are getting God's punishment for wrong deeds.
Some PLWH have guilt feelings about the infection and blame themselves.	People treat them disrespectful	Stigma
Shame	Loss	Talking behind their backs, giving signs to show that they are infected.
People feel ashamed to be with PLWH.	Struggle with loss of health, dreams, families.	Shy away
Rejection	Shame	Avoidance of PLWH when almost dying.
When infected especially women, they are forced out of home, and children are sent with the mother.	It is a shame to be infected and they cannot share.	Despise
Stigma	Rejection	Talking badly about PLWH.
PLWH are seen to be different and treated differently.	Being thrown out of homes and property taken away.	
Discrimination	Anger	
PLWH are passed by, nobody is ready to serve them, others are treated better.	Anger towards themselves, families and God.	
Loneliness	Unworthy	
People fear coming close to PLWH and affected families have no-one to share with.	Feeling worthless	
	Deserving God's punishment.	

	<p>Respect</p> <p>Disgrace</p> <p>Viewed as disgrace to families and communities.</p> <p>Fear of dying, losing families and people talking about their status.</p>		
<p>5</p> <p>How else could CBHC respond to the needs of PLWH?</p>	<p>Treat PLWH as humans</p> <p>Be with them even when dying.</p> <p>Comfort</p> <p>Need to be comforted when experiencing pain, loss.</p> <p>Guide affected</p> <p>Help children grow up.</p> <p>Help - forgive</p> <p>Share forgiveness and assurance.</p> <p>Show love</p> <p>Care for PLWH and affected.</p>	<p>Show true love</p> <p>Embrace</p> <p>PLWH and the affected families.</p> <p>Solidarity</p> <p>Stand with them from when they know status to when they are dying.</p> <p>Care, support</p> <p>Material and financial.</p> <p>Respect</p> <p>Treat with dignity.</p> <p>Advocate for them.</p> <p>Comfort the affected families.</p>	<p>Understanding</p> <p>More love</p> <p>Accept PLWH</p> <p>Encouragement even when it is hard.</p> <p>Compassion</p> <p>Show it to PLWH.</p> <p>Serve PLWH as other people.</p> <p>Care about the needs of PLWH and the affected families.</p>
<p>6</p> <p>What qualities of pastoral and spiritual care and counseling are needed?</p>	<p>Be willing to help</p> <p>Be present</p> <p>Be there when needed.</p> <p>Understanding</p> <p>Show understanding</p> <p>Caring</p> <p>Do not leave them</p>	<p>Forgiving communicate forgiveness</p> <p>Loving</p> <p>Showing love</p> <p>Not judging</p> <p>Having non-judgmental attitude.</p> <p>Supportive</p>	<p>Merciful</p> <p>Show mercy.</p> <p>Loving</p> <p>Show loving kindness.</p> <p>Serving</p> <p>Be ready and willing to serve PLWH and the affected families.</p>

	<p>alone, be concerned about their challenges.</p> <p>Loving</p> <p>Love them as they are.</p> <p>Non-judging</p> <p>Do not point fingers at them.</p> <p>Give hope</p> <p>Be appreciative of small things that PLWH do.</p>	<p>Source of support to PLWH and the affected families.</p> <p>Understand needs of infected and affected.</p>	<p>Understanding</p> <p>Be understanding of the condition and the issues affecting PLWH, the affected and the caregivers.</p> <p>Not condemning.</p> <p>Not seeing the PLWH as the bad ones getting God's punishment.</p>
7	<p>What would be expected of pastoral and spiritual caregivers in Plateau?</p> <p>Committed</p> <p>Be present, give time and material help.</p> <p>Present</p> <p>Available when called upon.</p> <p>Show love</p> <p>Respect PLWH</p> <p>Care for PLWH and the affected</p> <p>Friendship</p> <p>Make friends with PLWH.</p> <p>Very understanding</p> <p>Guidance</p> <p>Be a guide to affected families.</p> <p>Help families to reconcile</p>	<p>Spiritual guidance to PLWH and affected struggling families.</p> <p>Forgiving</p> <p>Help them to have forgiveness.</p> <p>Not blaming</p> <p>Not pointing fingers.</p> <p>Present</p> <p>Available when needed</p> <p>Understanding</p> <p>Form support and advocacy groups</p> <p>Caring for all people</p> <p>Commit time and resources</p> <p>Loving</p>	<p>Compassion</p> <p>Show compassionate care.</p> <p>Loving</p> <p>Love them even though they are infected.</p> <p>Be there -serving</p> <p>Willing to serve.</p> <p>Committed</p> <p>Commit time and resources to help.</p> <p>Caring</p> <p>Be involved.</p> <p>Love all people.</p>
8	<p>How often do PLWH come for support?</p> <p>Once a month</p> <p>Appointment dates</p>	<p>Once a month and during community visits.</p>	<p>Not known-people fear PLWH</p>

<p>9</p> <p>How else could pastoral and spiritual care help in the support of PLWH?</p>	<p>Prepare people- with fear of dying to die peacefully.</p> <p>Help affected families.</p> <p>Help with anger management</p> <p>Help to have peace.</p> <p>Reduce hatred.</p> <p>Education support</p> <p>Counseling to orphans.</p> <p>Advocate for rights of children and widows.</p> <p>Accept PLWH just like other people.</p> <p>Comfort to the dying.</p> <p>Treat PLWH who die with respect.</p> <p>All people must be encouraged to support PLWH and the affected.</p> <p>Socialize with PLWH and affected families.</p> <p>Teach more people how to help.</p>	<p>Encourage forgiveness.</p> <p>Do not say PLWH are being punished.</p> <p>Show God's love</p> <p>Encourage congregants to visit, pray and support PLWH and affected families.</p> <p>Link with parish minister and deacons.</p> <p>Care for the dying in their homes.</p> <p>Work with congregational minister.</p> <p>Send off the dead with respect.</p> <p>Form strong support groups.</p> <p>Train caregivers with HIV counseling.</p> <p>Train staff with spiritual care, knowledge and skills.</p> <p>Prepare and stand with PLWH even after death.</p> <p>Train more caregivers.</p> <p>Do not judge.</p>	<p>Sensitize the church.</p> <p>Train congregation about true pastoral care.</p> <p>Encourage members to volunteer to serve using spiritual care skills to support Hospital staff.</p> <p>Do not condemn.</p> <p>Love as Jesus did.</p>
<p>10</p> <p>Who else should be involved in the care and support of PLWH in Plateau?</p>	<p>Church leaders</p> <p>Pastors</p> <p>Deacons</p> <p>Women and youth leaders</p> <p>Village leaders</p>	<p>All religious leaders</p> <p>Female caregivers</p> <p>Male caregivers</p> <p>Community leaders</p>	<p>All people in congregation.</p> <p>Compassionate caregivers in communities.</p>

	People of goodwill Advocates		
11 To what extent has the Hospital's HIV/AIDS work impacted on other spiritual issues in the community of Plateau?	PLWH get: Medical care Nutritional supplements Education for orphans Voluntary counseling and testing Home visits Vocational training Income generation activities Referral for OI treatment Orphan care Love for PLWH by good example to staff Information about HIV is available Support reduces trauma and stigma in children.	Psychosocial support ARV Terminal care OI treatment Nutrition and livelihood support ie provision of farm input, contribution of food. Educational support Vocational training to affected and infected OVCs (selected) Continuous home visitation to the households, which has enhanced the sense of belonging. Staff showed love for PLWH and helped deal with trauma and grief for OVC. Improve the quality of lives - positive life. Encourage voluntary counseling and testing for couples and pregnant women and refer them to appropriate services required. Close follow-ups for PLWH to ensure adherence to drugs. Provide cost-sharing start-up capital for income-generating activities especially to those with interest and potential to do something, e.g. buy and	Medical care Home visits Education for orphans Voluntary counseling and testing

		<p>sell groceries, keep chickens.</p> <p>Train them on need for will-writing to protect their property and assets and prepare for their children's future.</p> <p>Educate them on general information re HIV/AIDS modes of transmission and preventive measures.</p> <p>Train church/ community leaders and volunteers on care of OVC and PLWH, stigma and discrimination reduction within the society towards PLWH.</p> <p>Train caregivers on how to stop discriminating against HIV+ Children.</p>		
12	How free are clients to disclose their status?	Not free to disclose as people shy away when knowing your status.	Only disclose freely to medical staff.	Nobody discusses it.
13	What is the level of the programme participation in HIV work?	Community not involved in care like the Hospital.	Is low compared to the need.	Do not know much.
14	Which spiritual resources are used in the care of PLWH?	-	Prayer	Prayer

From the responses to the 14 questions administered by the researcher given in table 9 above, the researcher made some data analysis and presentation as we shall see in section 3.3 below.

### 3.3 THE RCEA PLATEAU MISSION HOSPITAL: Data analysis and presentation

On responding to question one- how CBHC programme and staff responded to the HIV pandemic in Plateau, both the CBHC staff and HIV groups agreed on most of their

contributions, except that the CBHC group added “linking” onto the list. Only the congregation group had “visitation, food and medicine,” which were also found in the CBHC and HIV groups (refer to Table 9. above).

Concerning those involved in the care of PLWH, in question 2, the CBHC and HIV group had similar responses on the people involved in the care and support of the PLWH, but the congregation gave the group of deacons and volunteers as those involved (Ref. Table 9 above.)

On the type of PLWH needs and how they are met, (question 3), the CBHC and HIV groups saw needs of PLWH being met in similar ways. The congregational group differed in this, for they gave one visitation, which is common among the three, and added “through deacons.”(See table 9 above).

All of the three groups had five common responses with regards to unmet needs: in the CBHC, HIV and congregational groups; the CBHC and PLWH groups had other responses that were common between the two; the PLWH and congregational groups had three responses that were unique; the CBHC and congregational groups shared only two responses; the CBHC group gave three responses not found in the PLWH and congregational groups; the PLWH gave three responses not found in the CBHC or congregational groups (Table 9 has details).

All of the three groups had four common responses concerning what the alternative responses to HIV would be. The group of PLWH had one unique response, the CBHC had one and the congregation’s group also had one unique response. ( Ref. Table 9)

The three groups (CBHC, PLWH and congregation) had four common responses. Unique responses were received from the PLWH group -four; the CBHC – two; and the congregation – one (See table 6 responses to question 6).

All of the three groups had three common responses. (PLWH) and (CBHC) groups had two unique responses each (see responses in question 7 in table 9).

Concerning how often PLWH come for support, the PLWH group indicated twice how PLWH and the affected come for support, the CBHC group agreed, but the congregational group did not respond to this question (see question 8 in table 9)

The three groups agreed on three major areas: they saw pastoral care could help (Table 9 responses on question 9).

The three groups responses on those involved in the care of PLWH- All of the three groups had involved people in the church as care takers. The congregation's group saw that all people and caregivers were involved; PLWH saw that all church leaders, women and youth leaders, people advocating for rights and justice, and village leaders were involved; and the CBHC group saw that community leaders were also involved (Table 9. Question 10 responses).

On the impact of Hospital work on other pastoral care issues, the PLWH and CBHC groups agreed on 13 responses. The three groups agreed on three common responses, and the CBHC group had three unique responses (See table 9: responses on question 11).

On how free people are to disclose their status, the PLWH group indicated that people are not willing to disclose their status because the moment they do that, people shy away from them. On the other hand, the CBHC group said that people are free to disclose only to the personnel. The congregation's group said that nobody talks about disclosure (table 9; responses for question 12).

At the level of participation, the PLWH group said there was no participation; the CBHC said the level is low compared to the need; whereas the congregational group indicated that they did not know the level of participation (see table 9: responses to question 13).

Concerning spiritual resources, PLWH said the spiritual resource used is visitation; the CBHC and congregation's group said it is prayer (table 9: responses for question 14).

### **3.4 Evaluation**

The responses from the congregation were very few compared to those that the PLWH and the

CBHC supplied. This may have been due to the low profile they have adopted or lack of involvement. On the one hand, the responses the CBHC gave were indicative of the kind of work they do within the home-based care programme, and the need to improve the quality of service to PLWH and affected families. The PLWH commented on some areas of the programme that they are familiar with, and highlighted areas they felt need more attention and are not included in the programme. What may have influenced this is the fact that they are the ones who experience stigmatization and they were also speaking on behalf the OVC's experiences; they know what the needy areas are. The other reason is because they are fully aware of the needs that are met and those that are not met.

### **3.5 Concluding remarks**

Based on the above responses in the analysis and presentation, the researcher drew the following conclusions:

The coordinator,<sup>48</sup> nurses, field officer and volunteer care-givers of the CBHC programme all agreed that the CBHC renders support to PLWH, families affected by HIV, and to children orphaned through HIV (CBHC staff interview: 15 June, 2008). The CBHC team in the office and in the field carries out the support given to the PLWH, affected families, and OVC.

The OVC receive education and nutritional support through the programme. The CBHC coordinator, a nurse, together with other nurses, trained village volunteer care-givers (VVCG), and community health workers (CHW) are the ones who are involved in the care and support of PLWH in the community-based health care program at the Plateau Mission Hospital.

The staff meet the needs of PLWH by visiting them in the support groups and in homes of PLWH, counseling is conducted when PLWH come to the VCT centre, and when they go for referral at the centres run by the Moi Teaching and Referral Hospital for ARVs.

The PLWH are assisted to adhere to the treatment of ARV given to them, are also encouraged to

eat well and also receive nutritional supplements, and have their opportunistic infections treated when they visit the Hospital's main facility. Children orphaned through HIV are on the programme where they are supported with basic educational needs.

The medically trained staff said that removal of the PLWH experience of stigma by the church, denial, anger towards God, and discrimination are some of the unmet needs among the PLWH. The CBHC staff also said that some clients are not willing to disclose their status because of stigma and, at the same time, they are not willing to come for VCT for fear of being rejected by their own families.

The CBHC staff agreed that they can serve PLWH better by helping their clients work through denial and anger, and working with the communities to accept PLWH, to reduce stigma and help them get over their anger. The staff also felt that it will be helpful to have the support of the congregations, where the support groups are from (at the moment CBHC notes only a small percentage of involvement of non medical team).

The CBHC staff agreed that a spiritual model is seen to assist the Hospital in meeting the spiritual needs of PLWH. Other than the medical staff at Plateau and Moi Teaching and Referral Hospital centres, CBHC staff deem it to be a good opportunity for the involvement of the parish minister and other church leadership in the care and support of PLWA. This will make the Plateau Hospital run programme to involve other key stakeholders in the catchment area (community members, deacons, evangelists, men, women and youth leaders) in the congregations, where the PLWH come from.

The responses of the PLWH to the questionnaires were group responses. In their response, 35% feel loved and cared for, whereas 65% feel that they are regarded as a burden to their families.

All the PLWH said that Christians in the ten congregations had distanced themselves, and saw them (the PLWH) indifferently. Some PLWH have suffered stigma from Christians in the congregations and feel isolated by the church. Therefore, they feel that, apart from the nurses'

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<sup>48</sup> Esther J.: Brief Report of CBHC work in Plateau:3 July 2008

and volunteer care-givers in the communities, congregations and their overall leadership should be implementers of spiritual care to PLWH. They also feel that, apart from the medical and material support that they receive from Hospital staff, they also need encouragement, prayers, hope and guidance from Christians in the congregations and other members of their communities (interview PLWH group: Plateau July 5, 2008).

Due to lack of involvement, the church leaders regarded HIV/AIDS as extremely distanced from them.

The leaders in the RCEA Plateau parish connected HIV to promiscuity and therefore regarded PLWH as immoral and sinners. The parish minister of the RCEA Plateau parish acknowledged that, from the onset of the programme, the attitudes of church leadership in the parish were that of fear, condemnation, and rejection of PLWH (interview parish minister: July 5, 2008, Plateau).

Leaders observed that what resulted was a condemning attitude, people fearing to come closer to PLWH and avoiding any church activity with PLWH. Since they all believed that PLWH were immoral and any socialization with them could mar their own good names (Parish minister: 2008), social sidelining of PLWH and their families occurred, which further crippled Christian care and support for these people. This would not have happened had PLWH been treated like other members of the congregation or of the community within the congregations. In the long run PLWH were excluded<sup>49</sup> from visit encouragement, comfort, prayer, treatment with dignity, trauma counselling, and care of orphans of the terminally ill.

When members of congregations started dying of HIV, congregations and their leadership changed their stance on moralising HIV. After the interview, the leaders saw the need for their active involvement, integration of HIV in all the ministries of the church, and to have spiritual care as the key component of the care and support that the congregations should offer to all PLWH (congregations interview with parish minister: June 30, 2008, Plateau). The coordinator of the CBHC programme and her team<sup>50</sup> have also observed that, in the ten RCEA congregations

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<sup>49</sup> Interview: Parish minister: July 5 :2008).

<sup>50</sup> CBHC staff: interview with Esther Jepchumba: June 15: 2008: Plateau

in Plateau parish that surround the areas where the PLWH come from, they are more stigmatized than supported. Effects of the stigmatization are shown below:

- Anger
- Guilt
- Depression
- Loneliness
- Withdrawal
- Exploitation.
- Rejection
- Despair
- Loss of hope
- Meaninglessness

Finally, the researcher observed that all of the three groups interviewed were agreed that there is an urgent need for leaders of congregations, the CBHC's HIV/AIDS committee, the CBHC staff and all caregivers involved, to offer spiritual care. The spiritual approach would encompass the following aspects which the staff, committee and PLWH deemed important for holistic healing:

1. compassionate care
  2. unconditional love,
  3. acceptance,
  4. being with the PLWH at all times,
  5. praying with PLWH,
  6. visiting them in Hospital and in community support groups,
  7. counseling the infected and the affected,
  8. establishing congregational councils of HIV activists,
  9. organising weekend challenge programmes of standing in solidarity with PLWH to fight stigma and discrimination
  10. allowing participation of PLWH in the creation of awareness in the congregation,
  11. setting aside some days in the church calendar for celebrating (appreciating) the lives of PLWH, collecting gifts for them, and spending time with them,
  12. allowing PLWH to participate in the life of the church (leadership, projects, etc), and including HIV material in the sermons and liturgies.
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They also agreed to use the spiritual model to offer specialised counselling to PLWH who needed this and to advocate for justice and the rights of children orphaned through HIV.

The congregations<sup>51</sup> agreed to re-claim their calling by implementing the spiritual model to offer compassionate care to the infected and affected members in the church and the community that they have neglected for the last five years.

The CBHC staff<sup>52</sup> agreed that a spiritual model could assist the Hospital to counter stigmatization and to meet the spiritual needs of PLWH. Moreover, the CBHC staff deem this as a good opportunity for the involvement of the parish minister and entire church leadership in the care and support of PLWH. They believe that the spiritual model will help the Plateau Hospital run programme to involve other key inactive stakeholders of the catchment areas in the holistic approach to care and support of PLWH. The key stakeholders include:

- Hospital staff,
- community members,
- parish ministers,
- community leaders,
- deacons,
- evangelists,
- leaders of women's, men's and youth groups,
- other religious groups,
- the PLWH,
- affected families, and
- OVC in the Hospital's catchment area.

The holistic healing, which encompasses empathic understanding, hope, meaning, understanding, unconditional love and acceptance, could be realized with change of positioning at the Hospital in terms of strategy, and also of key players in the care and support of PLWH and affected families. It also entails a change of the negative attitude, which is a breeding ground for stigma, change of perceptions, and increased diaconic and *koinonic* aspects in the relationships between

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<sup>51</sup> Congregations: interview with Rev. Daniel Barno, parish minister, June 30, 2008, Plateau.

<sup>52</sup> CBHC staff: interview with Esther Jepchumba, 15 June, 2008.

caregivers and those cared for. The researcher in the following chapter will look at the challenge HIV/AIDS poses to spiritual care and the quest of people living with HIV for meaning and dignity.

## **CHAPTER 4: HIV AND AIDS AS A CHALLENGE TO SPIRITUAL CARE: THE QUEST FOR MEANING AND DIGNITY**

### **4.1 Introduction**

HIV/AIDS presents great challenges for any meaningful intervention strategies. This calls for a comprehensive approach in the care and support of the infected and affected families and communities. With provision of medical care to PLWH, the health facilities have done much for these people. Nevertheless, people who have received ARV's and other medication for opportunistic infections (OI) have suffered from stigma and discrimination to such an extent that they die, not because the medication has failed, but due to the negative feelings and attitudes towards them, not to mention the un-conducive environment. The case below is one among many that tells of the negative effects of stigma<sup>53</sup> and stigmatization on PLWH and the affected families.

In this chapter, the researcher will begin by assessing the effects of stigma on and the discrimination against PLWH and their affected families (in section 4.2), and then discuss the medical approaches to health care (in sections 4.3 and 4.4). The researcher will also describe a systems approach to care (section 4.5) and thereafter explain the importance of interdisciplinary approaches (section 4.6). This will be followed by the definition of pastoral care and practical theology, and discuss pastoral care and counseling (in sections 4.7, 4.8, 4.9 and 4.10). Finally, the researcher will demonstrate understanding of PLWH and affected families, explain the importance of spiritual care to PLWH and shed light on the role of God images in therapy among PLWH (4.11, 4.12 and 4.13). The discussion of the proposed approach of spiritual care by means of a pastoral care model will then follow. The ministry of the church to PLWH and the Conclusion to the chapter will soon follow.

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<sup>53</sup> Brown (2004) in her Dissertation for the Doctor of Theology Degree, Stellenbosch University has discussed the stigma, and related terms such as alienation, prejudice in relation to people living with HIV.

#### 4.2 The impact of HIV/AIDS and the challenge of silence, stigma<sup>54</sup> and discrimination

HIV AIDS has affected the infected and affected communities in immensely negative ways. In Plateau community in particular, the infected have no voice. Apart from the CBHC programme, they hardly have activists on the ground to counter the indifference they experience. Children have been psychologically challenged as they have no choice but to experience the devastating negative feelings and attitudes described below.

My mother was very sick for four months. My dad made her sleep in the kitchen outside the main house. He did not want anybody to sit with her. She was given her separate cup, plate, spoon, bedding and basin. Sometimes I sneaked into the house when my father had left to take local beer to help her when she was in pain. I cooked food for her and quickly went away. My father wanted her to die, accusing her of being a bad woman. Whenever he discovered I had gone in, he beat me up. This made me run away from home and I had to go to the big city to look for a job. After four months my mother died alone in the kitchen. (Leah: Interview: July 2008: Plateau).

Since the outbreak of HIV/AIDS in the mid-1980s, the number of infections has increased daily, whilst its effects doubled with the increasing number of sick people, desperate widows and widowers impoverished by the illness of the deceased husbands and wives, orphans and vulnerable children, the sick community and/or society, and the weary economy (Dube, W. 2004: Africa praying: V).

The HIV/AIDS pandemic has resulted in (i) children being left with grandparents, or children left in the care of their older siblings who are in dire need of care and guidance, (ii) women

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<sup>54</sup> “Unfortunately, HIV/AIDS carries a strong stigma. Many people believe that those infected with HIV somehow did something to ‘deserve’ AIDS. Despite several years of publicity and education, many only know that HIV/AIDS kills, so they want nothing to do with persons who are HIV positive. Many people still react negatively towards a friend or even family member who lets it be known that they are infected. The result is that many who are HIV positive feel compelled to live in secrecy. As if facing a life-threatening illness is not hard enough, they have to hide to avoid being the target of unfounded fear, hate, and bigotry born of ignorance. In short, at a time when the support of the community is most needed, it is not available. Rather than being supported, people living with HIV/AIDS often become outcasts” (Cory, Richard B: U.M. Family HIV/AIDS

dispossessed<sup>55</sup> of belongings by relatives and therefore in need of counseling,<sup>56</sup> care and support, (iii) infected and dying people with parting cries who must be prepared to finalize their family businesses and be encouraged to die peacefully and with dignity.

What makes it even worse are the outdated negative feelings and attitudes that were present in the mid-1980s where the infected were labeled immoral, non-abiders by church law, bad people who were facing God's judgment.

There also are many deceased young people, women and men, who need to receive their “last respects” and must be buried,<sup>57</sup> and numerous people living with HIV who, daily, are experiencing enormous stigma<sup>58</sup> and thus need care and support. We also have affected communities who are completely lost in the existential realities of “hopelessness, despair, fear, and guilt, who need pastoral guidance that will help them, find meaning”<sup>59</sup> and understand God's unfailing presence in their suffering.

The pandemic has left the society with broken relationships, rejection, a desperate search for a cure, vulnerable baby girls, young girls, boys and women.

There are many initiatives from key players in HIV intervention: governments, non-governmental organizations, church-based institutions and private individuals who are doing what they can to promote the healing of individuals, families, the community and societal brokenness. However, this does not mean that all people are automatically equipped with skills and knowledge to deal with HIV/AIDS. Some churches are still struggling to understand the basic facts of HIV, since they have had no training besides their professional training. Some have been inadequately prepared to implement both the theoretical and practical components in

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Network: Florida).

<sup>55</sup> Refer to the case study in Appendix 6.

<sup>56</sup> Van Dyk, A. 2008. HIV/AIDS care and counseling: A multidisciplinary approach. Maskew Miller: Cape Town.

<sup>57</sup> Refer to case study in Appendix 1.

<sup>58</sup> CBHC. 2008. CBHC Staff Report: Plateau Mission Hospital: CBHC and RCEA Diaconal Ministry Report (2007) to NETACT Book Project: Eldoret: Care (unpublished).

<sup>59</sup> Dube, W.2004. Africa praying: & PLWH: 2008: PLWH responses: Plateau, Esther: 2008: Interview, June 15 Plateau.

HIV/AIDS care and management.

The greatest challenge of the pandemic is how best HIV interventions could be faithfully and harmoniously integrated in existing organizational activities. This requires integration without compromising the latter or the former, hence the need for sensitivity, relevance, practicability and new ways of understanding. This could be achieved through the holistic approach of spiritual care as a dimension of pastoral care.

The multi-faceted demands of HIV present theology with the challenge<sup>60</sup> of putting theological factors together, and provides an alternative basis for medicine, thus recapturing a holistic approach. God uses the involvement of both theology and medicine in dealing with humankind's aspects of soul and body. The fusion of theology and medical science helps to overcome the obstacle of dualism (De Gruchy: 1999). At this point, it is fitting to explore the medical models used in health care before we turn to theological perspectives.

### **4.3 The Biomedical Model of health care for PLWH**

Tabifor (2002:135) has described the health care approach to care and support as being not solely through drug therapy. He adds that the health system addresses HIV/AIDS and HIV treatment by the use of the anti-retroviral drugs, which delay the disease's progression, and other medications that treat OI's.

Today, the biomedical<sup>61</sup> approach is the dominant model in medicine and it has guided the thinking of most health practitioners for hundreds of years (Taylor: 1986). For illness, this model acknowledges only biological explanations, which are very important, but they form an

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<sup>60</sup> De Gruchy, J. 1999. *Salvation as healing and humanization: An ambulance of the wrong colour: Health professionals, human rights and ethics in South Africa*. Ed. Laurel Baldwin Ragaven. Rondebosch: UCT.

<sup>61</sup> The dualistic view of the separation in the person supports this model in health care. The person is seen to be composed of body and soul, and this model's emphasis is the body. The physical and material are important. Therefore, the body's health takes precedence over the health of the soul. This position further separates the person from the family, culture and environment, hence promoting individualism. The relational dimension of illness is ignored and this leads to a communication breakdown between medical caregivers and the PLWH. The end reality is isolation of the PLWH from the needed support system (Louw, 2008:39ff).

incomplete<sup>62</sup> picture of the causes of illness. This model does not acknowledge the interaction between mind and body. It seeks the cause of disorder rather than examine a range of contributory factors (Lakhan: 2006).

In the biomedical model,<sup>63</sup> health has traditionally been equated to the absence of disease. A lack of fundamental pathology was thought to define one's health as good, whereas biologically driven pathogens and conditions would give an individual poor health and a label of "diseased." However, this was later viewed as a narrow scope on health, which limited an understanding of wellbeing, and it thwarted efforts for treatment and, perhaps more importantly, suppressed prevention measures.

The focus of this model is on the physical causes of disease. The physician is concerned with diet, pain, history, and familial incidence, while considering empirical signs and symptoms as paramount. Diagnosis after presentation involves objective laboratory tests and monitoring vital signs, such as temperature, pulse and blood pressure, which would form the sole basis of any finding. For therapy to take place, the doctor prescribes a medical plan for the patient, based on the biological etiology and pathogenesis.

The biomedical model is reductionist, because it defines illness only in terms of biological processes and ignores the psychological and social factors (Taylor 1995, cited in Whitman 1999). The diagnosis is based on a combination of psychological factors and standard laboratory tests. For therapy to take place, the physician discusses interventions with special attention to behaviour and lifestyles that could influence pain and adherence to the treatment plan.

The patient<sup>64</sup> is involved in formulating and implementing the plan, and maintains a supportive relationship with the clinician. This model, therefore, claims that illness is caused by a combination of biological, psychological and social factors.

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<sup>62</sup> Lakhan E.S. 2006, August 3.

<sup>63</sup> Lakhan E.S., <http://cnx.org/content/m13589/latest/> August 3, 2006.

<sup>64</sup> The patient can no longer be regarded as a passive victim for he/she is to be responsible for treatment, if necessary.

The biomedical approach to health and illness is very dominant in the process of curing and healing in today's world. In the light of the medical approach, doctors prefer to speak of their work as curing or treating, rather than healing (Louw, 2008:36). In contrast, Wilkinson (1998:1) regards healing as pointing in the direction of non-medical methods of treatment.

As a model, the biomedical approach has theories holding that bacteria influence the medical condition where illness is caused by infections, viruses and bacteria. On the one hand, the epidemiological theory considers the relationship between illness and social factors. On the other hand, the mechanistic theory holds that the human body functions like a machine that can be repaired by means of medical surgery; the cellular theory examines changes, which take place in cells; and the psychosomatic theory views illness as closely related to neurological and psychological factors.

The biomedical approach to health care, as we have seen above, has several implications. The advantages are that it offers health care with accurate diagnosis and sophisticated methods of treatment, and methods for care and treatment through which modern medicine is practiced. However, this also means that, through the medical model and medical science as a whole, the patient, as a person, is replaced by the emphasis on the diagnostic skills of the doctor. More so, the person is replaced by the analyses of technological gadgets - computers, x-ray machines, machines in the operating theatre, and the prescriptive power of pharmaceutical industries.

This means that the model uses analytical and diagnostic approaches<sup>65</sup> that value knowledge of the human physiology and biomedical functions, and the use of relevant apparatus, instruments and medication in the care of the patient. As a result, the physician uses technology and chemicals in controlling the life of the sick.

Pathology (bacteria, viruses, and death) becomes more important than the dynamics of life (the totality). This leads to a split in the interests of the person (the sickness and the sick) where the disease is seen as separate from the person (see the distinction: subject - object) leading to a rational understanding of illness and health. Identifying the problem and curing also become

'opposing poles'<sup>66</sup> in the care of the sick.

The end results of both the above mentioned approaches<sup>67</sup> are:

1. distancing the patient from the physician;
2. division in a person's being – a distinction between sickness and the sick person;
3. objectifying human beings with no concern for the cultural/spiritual aspects;
4. dismemberment (fragmentation) - dissecting the person so as to study some aspects and not considering the person as an entity within relationships;
5. mechanizing the human being - curing the afflicted part with antibiotics and/or surgery;
6. Treatment of symptoms by means of pharmaceutical prescription.

With the impact of HIV and AIDS, in attempts to offer the best care, the medical system has arrived at a new understanding that recognizes the importance of the spiritual aspect, as we see below.

#### **4.4 The Bio-psycho-socio model of health and illness**

There have been certain changes that have led to dissatisfaction with the biomedical model. The bio-psycho-social (BPS) model<sup>68</sup> considers a number of factors at work: it seeks the link between mind and body and advocates a holistic approach to health care. This holistic view of health in sound medical application is primarily based on the BPS model<sup>69</sup> of health and illness. The concept of wellness is particularly stressed where a good quality of life and strong relationships accompany the state of being in good health, based on the BPS model.

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<sup>65</sup> Louw DJ. 2008. *Cura vitae: Illness and the healing of life*. Lux Verbi: Wellington, 38-39.

<sup>66</sup> The biomedical dualistic stance goes further to approach people pathologically, including PLWH, as being separate from their own social context, family, culture, and the known environment. This removes people from their support system. Through dualism, people are further regarded as objects of study, hence ignoring the spiritual and cultural dimensions of life (Louw: 2008:39). Instead, the patient living with HIV should be treated as a unique human person within the context of the community system.

<sup>67</sup> Biomedical and the bio-psycho-social approaches to health care.

<sup>68</sup> Lakhan:(2006).

<sup>69</sup> This model uses psychological and social, as well as biological explanations, to provide a full picture of health and illness.

George Engel (1977), an American psychiatrist, introduced the BPS model. This model accounted for biological, psychological, and sociological interconnected spectrums - each as a system of the body. The BPS model aims at ascertaining<sup>70</sup> psycho-social processes that may cause the chief complaint, for instance recent life stressors and behaviours.

#### **4.4.1 A new understanding in medicine: Bio-Psycho-Social plus Spiritual**

With the physician's new understanding, American medical schools (AMS) offer the bio-psycho-social approach to medicine that pays attention to spiritual issues. However, Harold G. Koenig, associate professor of Psychiatry and Medicine at Duke University's Medical Center, said, "HIV/AIDS ... is a pretty nasty illness. It threatens people's lives, their way of life, their relationships ... it brings up a lot of spiritual issues given the backdrop." He adds, "Physicians need to address these issues to practice whole person medicine." Furthermore, the AMS's project committee on spirituality, cultural issues, and end-of-life care, chaired by Puchalski, in 1999 reported that:

“Medical students should have an understanding of, and respect for, the role of clergy and other spiritual leaders as well as how to collaborate with them on behalf of patients' physical and/or spiritual needs” (Association of American Medical Colleges, 1999, p.26a<sup>71</sup>).

Puchalski believes that issues beyond the comfort and expertise of doctors should be referred to religious or spiritual experts, whom she sees as colleagues and partners in the patients' care team (AAMC: 1999). Therefore, with reference to the above, it is clear that the recognition of the importance of spirituality, irrespective of religious affiliations, in the care and healing of PLWH, OVC and the affected families in the Plateau Hospital, will not only improve the quality of service but also improve the quality of life. This will mean participation of all stakeholders in the care-giving (medical staff, community leadership, the clergy and church leadership, families,

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<sup>70</sup> Lakhan E.S in, <http://cnx.org/content/m13589/latest/>, accessed - August 3, 2006.

<sup>71</sup> [http://hrsa.gov/publications/february\\_2002.htm](http://hrsa.gov/publications/february_2002.htm)). Accessed August 2008.

affected and infected). For the Plateau Hospital to do this, a frame of reference (a new stance in the approach to care) is needed. This includes understanding the needs and challenges of PLWH from the medical, spiritual and social perspective.

Kriel(1988:15)observed in the case of South African health and healing that treatment of disease is more that clinical. He added that in the 1980s, only 10% of health problems were clinically treated by doctors, drugs, and hospitals. Moreover, the biological mechanisms were seen as rarely the exclusive causes of illnesses. The researcher contends therefore that other non-biological mechanisms that cause illness and bad health require non-medical clinical approaches for health and healing. This brings us to the systems approach to health care in the following section.

#### **4.5 A holistic Systemic<sup>72</sup> Model to care of PLWH**

The holistic systemic approach, used by biomedical personnel and any other caregivers, should regard a person as a relational and social being acting within a cultural context. This implies that medical science should consider the psychosomatic and socio-cultural side of the illness and health continuum.

According to the holistic systemic approach, a person's being is of prime importance, opposed to the functions of the person's body parts. In this approach, the core tripartite components of humanity are morality, spirituality and the social nature. These components interact in a dynamic process of generating meaning. Furthermore, this approach implies that, for the total health and wellness of a person, societal structures and relationships should also be healed (Louw: 2008). The researcher is convinced that application of a systems approach in the care and support of PLWH, affected families and communities will help shift dysfunctional positions that sustain stigma, hence promote appropriate being functions in the therapeutic space and relationships between the caregivers in the hospital/communities and those being cared for. The results of

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<sup>72</sup> “This is, according to systems thinking, an attempt to understand and to interpret the dynamics of inter-relatedness and interconnectedness ... applied in anthropology; systems thinking assesses the human person as a whole. A human being ... is more than the sum total of its parts. And in Christian theology, systems thinking represents a covenantal understanding of life, space and relationships” (Louw: 2005. *Mechanics of the human*

using the systems approach will be an improved quality of our being functions, relationships, values, perceptions and growth in the interactions between therapists and clients - hence healing.

#### 4.6 Inter-disciplinary approaches to care giving

According to De Gruchy,<sup>73</sup> theology is being challenged to put theological approaches together and help to provide an alternative basis for medicine, and recapture the holistic approach. He uses the involvement of both theology and medicine in dealing with humankind from opposites: soul and body. The fusion of theology and medical science helps to overcome the obstacle of dualism. For purposes of this paper, the researcher will discuss in the following section vital components that enhance the holistic approach to care and support of people living with HIV. Through the spiritual approach to people living with HIV and AIDS, practical theology, pastoral theology, pastoral care, and counseling as a way of care to people living with HIV/AIDS are key in implementation of an integrated approach.

Louw (1999:25) has noted the challenge of pastoral care as being able to develop an interdisciplinary approach without losing its contribution to therapy. While discussing the implications of definition of pastoral care by Heitink (1977:75), Louw (1999:31) observes that pastoral care has a duty to discover and describe its own identity in relation to the other helping disciplines (for example social work and psychology. On pastoral care as cure of human souls in Louw (1991:20) sees *cura animarum* as the care of the total person which entails more than their psychological, social, physical components.

Louw (1999:21) adds that soul care is about people and the centre of their existence, their focus on God and dependence upon Him. More so, this describes a very special process of caring for human life because it is created by God and belongs to Him.

Allen (1995:27) echoes what Louw, De Gruchy, and Heitink have said above by seeing the need of integrating the spiritual into other dimensions and contexts. He calls for a constant theological

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<sup>73</sup> *soul*, p. 24).  
De Gruchy, J. (1999). *Salvation as healing and humanization: An ambulance of the wrong colour: Health*

reflection, study of anthropology and incorporation of the insights of other medical scientific inquiry. Based on Allen's, Louw's, Heitink's and De Gruchy's contributions above, the researcher stresses that integration will foster multidisciplinary teamwork in care and support of people living with HIV and other related health needs.

Pastoral theology and pastoral care are disciplines concerned with the spiritual dimension of our being human. Due to the limitations of a biomedical model, and in the light of the situation at Plateau mission hospital, this dimension needs more emphasis within a therapeutic approach at this hospital. In the following section, the paper will briefly discuss practical theology, pastoral theology, pastoral care, counseling, God-Images and the role of the church in the ministry to PLWH as vital components of holistic systemic spiritual care of PLWH.

#### **4.7 Practical Theology Defined**

Louw (2008:18) defines Practical Theology as a science that reflects on the deeds of God as related to the praxis of faith within a vivid social, cultural and contextual encounter between God and human beings. He also points out that Practical Theology is about the praxis of the *ecclesia* as related to the praxis of God within cultural contexts and communities of faith without bypassing the existential realities of life. Heitink defines Practical Theology as a theory of action that is empirically oriented to the theological theory of the mediation of the Christian faith in the praxis of modern society. In his definition, Heitink (1977:6-7) like Anderson (2001)<sup>74</sup> distinguishes the praxis as mediation of Christian faith from the praxis of modern society.

For Heitink (1977), the praxis of mediation is about the objective content, the core of Christian conviction. It is a form of praxis that deals with how human ministry communicates the unique content of God's saving intention and actions as revealed dogma (Anderson 2001:25). On the other hand, the praxis of modern society concerns the domain of action where individuals and groups, motivated by their personal ideals and driven by varying interests, make specific choices and pursue specific goals in their everyday lives, mutual relationships, marriage, family and

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*professionals, human rights and ethics in South Africa*. Ed. Laurel Baldwin Ragaven. Rondebosch: UCT.  
<sup>74</sup> Anderson, RS.2001: The shape of Practical Theology: Empowering ministry with theological praxis. Downers

workplace.

Anderson (2001:25) adds that, as a theology of action, in Heitink's view, Practical Theology draws heavily on the paradigm of social sciences rather than humanities for its method. Practical Theology is more than a mere practice, for it is a strategic perspective that links the hermeneutical with the empirical so as to achieve an integrative theological model that underlies the theological task as a whole (Browning, D. S. 1976)

Anderson (25:2001) quotes Ballard and Pritchard as saying that "Practical theology must take on the characteristics of theology as it too is descriptive, normative, critical, and apologetic. More so, practical theology is viewed as the means whereby the day to day life of the church in all its dimensions is scrutinized in the light of the gospel and related to the demands and challenges of the present day, in a dialogue that both shapes Christian practice and influences the world" (2001:26).

#### **4.8 Pastoral theology**

Pastoral theology is the pastoral perspective on the activities of the pastor and congregation (Hiltner 1959:19, as quoted in Louw (1994)<sup>75</sup> .

##### **4.8.1 Pastoral care as an important part of care to PLWH**

Louw (1994:22) quotes Hiltner as viewing pastoral care as a functional term, which denotes healing, not only in terms of salvation, but also the healing of all human functions. Moreover, pastoral care is seen to be a professional and academic field in theological education, as well as within the practical theological mode of comfort with praxis principles.<sup>76</sup> Hiltner further argues that all actions of the caregiver should be understood from the shepherding<sup>77</sup> perspective. Therefore, pastoral care implies more than empathy, and functions to heal, sustain, guide, reconcile, nurture, liberate, empower, and interpret (Louw: 2008:75-77).

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Grove: Intervarsity Press, p. 25

<sup>75</sup> Louw, DJ. 1994. *A pastoral hermeneutic of care and encounter*. Goodwood: National Book Printers, 22-23.

<sup>76</sup> Louw, DJ. 2008. *Cura vitae: Illness and the healing of life*. Lux Verbi: Wellington, 73-75.

<sup>77</sup> It is connected to the shepherding perspective in Scripture by the shepherd metaphor being viewed as an expression of God's loving care for human beings in need (Louw 1994:22).

#### **4.9 Pastoral Care and Counseling**

Pastoral counseling is one of the dimensions of pastoral care (Gichinga, E. 1999:22). It is the type of counseling that addresses the client's physical, emotional, spiritual, intellectual, social and environmental needs. By means of pastoral counseling, counselors nurture clients by acceptance, compassion, care, love, empathy, and guidance, and treat the clients with unconditional positive regard. Pastoral counseling aims at providing troubled people with care within the church and community.

Secondly, pastoral counseling is an interpersonal relationship which aims to help free a person's capacity to live his/her life as God's child, to grow as a person and become more mature in Christ. Van Lierop (1992:2) adds that, through pastoral counseling, the client is guided to find and understand him/herself and to clarify and solve his/her problems.

Thirdly, pastoral counseling is a helping relationship of care, compassion and concern that provides an opportunity for issues of faith and spirituality to surface. Through counseling, support is offered to others by entering into their world for a short time, and by the counselor's listening presence where life is seen through the client's eyes when they begin to express what is deep inside them. In the process of counseling, counselors grow into understanding by attentive listening and by means of sensitive questions and comments, thus helping clients to find fresh meaning and view their problems in a different way (Fr. Osb:2005,32: ).

Last but not least, for the purposes of this paper, pastoral counseling is defined as a helping relationship undertaken by women and men of faith, in which these people agree explicitly to give time, attention, and respect to another person infected or uninfected by HIV/AIDS, so that they have the opportunity of exploring his/her thoughts, feelings and behaviour - the cause of his/her present situation.

Pastoral counseling recognizes the particular importance of questions of faith as well as ultimate concerns about life and death, values and meanings. It aims to help people to discover and clarify ways of living more resourcefully and thus to enable them to achieve a greater sense of well-

being. It is a relationship with a purpose that is carried out within agreed boundaries, in which one person helps others to help themselves (Fr. Osb, 2005:126).

#### **4.10 Counseling as a way of caring for PLWH**

Counseling is a facilitative process<sup>78</sup> through which the counselor has a special working relationship using specific skills and knowledge to help a client to develop an understanding of the self, attain emotional acceptance and growth, and to develop personal resources aimed at managing his/ her own problems more effectively, thus being empowered to become a more effective self-helper.

HIV/AIDS counseling focuses on the affective (emotions/feelings), cognitive (thinking and understanding), behavioural (doing) and/or a combination of the affective, cognitive and behavioural. Concerning the main goal of counseling, Alta van Dyk (2008:220), in her book *HIVAIDS care and counseling* quotes Johnson:

'The aim of counseling with the HIV positive individual is therefore to focus on life beyond the infection and not to dwell unnecessarily on the constraints of the disease' (Johnson 2003:3).

This situates the counselor's work soon within or after disclosure of HIV+ status, with the aim of helping the PLWH to improve his/her quality of life with knowledge of the status, to manage problems emanating from this reality, and develop skills for coping.

Generally, the counselor moves through four phases<sup>79</sup> in a working relationship with the client:

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<sup>78</sup> "We cannot heal every wound and solve every problem in one hour. Pastoral care with someone whose life has been touched by HIV requires time, patience, and the development of a relationship. Our role is to come alongside of people and support them, be present with them. It is not to answer every question and give the solution to every problem. We must be patient as people work through the stages of grief and the myriad of issues that surround HIV." (Cory, Richard B.: U.M. Family HIV/AIDS Network: Florida)

<sup>79</sup> "As an approach to helping people living with HIV, through counseling , he/she builds a relationship with the client, helps the client to tell his/her story and explores the problem to develop increased mutual understanding. This leads the client to develop a plan of action. Through this, the client explores various options, chooses an alternative option and forms an action plan, comes up with what to do and what support is needed, explores the

(i) establishing rapport, (ii) creating an environment for the client to tell his/her story (iii) clear understanding by both counselor and client of the problem; and (iv) determination of an interventionist strategy or action.

Together with the above, the pastoral perspective of counseling<sup>80</sup> adds: (v) ensuring a caring system through empathetic space (and understanding); (vi) teaching how to cope in a more meaningful way with different life issues of problems; and (vii) assessing and utilizing appropriate God-images in the establishment of a mature spiritual stance in life.

For Plateau hospital to implement a holistic spiritual systemic approach to the care and support of PLWH, it is necessary to have clarity on the spiritual needs in the existential issues of PLWH as we shall see below.

#### **4.11 Understanding PLWH and their affected Families**

Tabifor (2002:130-131) states that the dignity of human sexuality and the AIDS challenge underscore the need to understand the feelings<sup>81</sup> and attitudes of people who have been tested and diagnosed as HIV positive. Therefore, in the caring relationship, it is important to take into consideration the reactions of people living with HIV.

As we shall see in the illustration below, PLWH reactions are noted in the emotional needs which the researcher has established as interconnected with their spiritual concerns. As depicted in the spiritual column, a person living with HIV needs security and God's compassion, an experience of connection, communication of forgiveness and reconciliation in order to experience and communicate dignity, and to experience *shalom*, acceptance and comfort in grieving and loss (De la Porte in Dube:2003). According to De la Porte, the caregivers should be able to address these

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understanding, explores feelings, considers options, chooses alternatives, feels understood, shares the story, understands how he/she feels and why, creates trust with the helper, opens and shares, feels safe with one willing to support” (Van Dyk 2008:220-227).

<sup>80</sup> In counseling , the therapist/counselor uses the necessary skills in counseling PLWH: attention, listening, probing/questioning, clarification, reflective commenting, summarizing, integrating communication skills, silence and immediacy.

<sup>81</sup> Tabifor (2002) discusses the phases of shock, anger, denial, bargaining, depression and acceptance among people who have tested HIV positive. Map International (1996: 7) has an elaborate discussion of feelings and attitudes of people living with HIV, families of the infected persons, and the church/communities or societies

spiritual aspects in a practical manner. Also important are identification and mobilization of internal and external spiritual resources available to PLWH and being connected to relevant spiritual leaders for the necessary care (Dube: 131).

PLWH, children orphaned through HIV<sup>82</sup> and those who have lost their loved ones through HIV suffer psychological stress,<sup>83</sup> particularly when they have to confront the traumatic effects of HIV,<sup>84</sup> and when they see the graves of their deceased loved ones. Some children drop out of school because they have nobody to continue paying their fees, because they must take care of their dying parents, or because they must adopt adult roles of providing for their siblings after the death of their parents.

Children grieve profoundly and their emotions fluctuate between being happy when they are with friends, to being deeply distressed at other times. This renders them vulnerable to abuse. Due to child abuse, orphans and vulnerable children suffer from psychological problems, such as depression and low self-esteem. This results in their taking risks, including some that can cause their contracting HIV.

The complexity of their situation exposes children to exploitation and abuse. Children need love, affection and attention. This implies time with their caregivers, which may include laughing and enjoying themselves during counseling available for children, i.e. the sharing of experiences, play therapy and recreation therapy for vulnerable children. For them to be safeguarded from HIV infections, they also need protection from abuse, exploitation and risky behaviour. This can be done by equipping them with life skills. Understanding what the needs of children and PLWH are induces caregivers to offer them the needed support, as shall be seen below.

In referring to what caregivers should offer, Cory identifies the following six simple but important interactions that he considered necessary to give to PLWH, as well as those affected by

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from where the PLWH come.

<sup>82</sup> Refer to case study 2 in Appendix 2.

<sup>83</sup> Children experience shock, grief and trauma after the death of their parents. This creates much stress in their relationships with other caregivers' ways of coping, and this leads to misunderstandings and conflicts with caregivers or people with whom they interact.

<sup>84</sup> Severe skin infections - (herpes Zoster), or skin cancer, and immobility (particularly when bed-ridden).

the pandemic: friendship, empathic understanding (a shoulder to cry on), hugs (comfort), being functions, kindness and dignity. The interactions are captured below:

"... the most important thing they can do is to be a friend.  
That may mean just going through life as usual,  
providing a shoulder to cry on, maybe a comforting  
hug, or maybe just simply being there. Treating those  
with HIV/AIDS with kindness and dignity is by far  
the greatest gift that can be given ." (Cory: accessed June 2008)

CBHC (2003) noted that there are certain times when caregivers are driven away and, instead of meeting PLWH when they are most needed, they rather shy away:

"Communities socialize with people living with HIV when  
their health status is still fair but with health deterioration,  
the community tends to shy away." (CBHC: 2003.p8)

Due to ignorance and stigma, most people in the community associate HIV with bad or immoral behaviour of the infected. This dictates the rules of the social space for PLWH or their affected families. PLWH may be excluded, and their families often stigmatized<sup>85</sup> because of their association with a person<sup>86</sup> living with HIV. Women are usually blamed for infecting their husbands, or for any bad behaviour of their children, hence increasing the stigma, particularly when their child is living with HIV. Some women suffer violent abuse, discrimination, exclusion from community activities and even being sent away and their property<sup>87</sup> taken by their late husband's family. Culturally, men<sup>88</sup> are not supposed to cry, but they too experience many

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<sup>85</sup> Some people, who visit the homes of PLWH, fear to eat food from their houses, because they believe it is contaminated. Others flatly refuse to visit them for fear of being infected. Due to stigma and discrimination, it is difficult for parents and children of people living with HIV to talk openly about the issues they face and to seek appropriate support.

<sup>86</sup> This could be a son, brother, husband or wife, cousin, uncle, niece, nephew or grandparent.

<sup>87</sup> Refer to Adelaide, case study 3 in Appendix 6.

<sup>88</sup> In the Sabaot culture (where the researcher comes from), if a man cries, or shows emotions, it means that he is weak and hence lacking warrior qualities.

emotional problems and need psychological support.

#### **4.12 Spiritual<sup>89</sup> care as an important aspect of Pastoral care to PLWH**

When discussing the spiritual dimension of all human problems in his book *Basic types of pastoral care and counseling*, Clinebell (1994:106) says that there are religious existential<sup>90</sup> aspects that are obvious in certain types of problems. HRSA (2008/03/22) underscores this point by putting across that all people, irrespective of their religious affiliations, have belief systems. Their belief systems influence the type of care that is needed and the direction that the healing is likely to take. The researcher is in agreement with what HRSA has to say below regarding the importance of patients' belief systems, which makes it inexcusable to ignore patients' spiritual realm in health care.

“Whether you know it or not, patients have belief systems and they may not be seen .... these belief systems have implications for the care you are giving, so it is good to find out about them.

For some people – particularly those with HIV/AIDS - the belief systems may have something to do with God and punishment and why they (PLWH) are in that position.

Health means more than just physical health....

Holistic health means taking care of ourselves not only physically, but also mentally and spiritually. Our health ... not only our spiritual and emotional health but also our physical health .... is an indicator of our spirituality ”

(HRSA:2002: February).

HRSA underscores the need for a holistic approach to health and healing and in this case the

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<sup>89</sup> Spiritual care to People living with HIV/AIDS is based on the spirituality of being human. This entails being functions that facilitates linkages and integration of psychological and theological understanding of maturity. This also means spirituality that considers seriously human relationships that would enhance creation of therapeutic space.

<sup>90</sup> In his book *Cura vitae: Illness and the healing of life*, Louw (2008:65-67) categorically emphasizes existential issues such as anxiety, experience of loss and rejection, guilt/shame, despair/doubt, helplessness/vulnerability, frustration/anger, disappointment and frustration, and structural issues such as poverty/unemployment, violence/crime.

centrality of spiritual care. This could be achieved by examining the belief systems in terms of PLWH and the affected families' God -Images as we shall see in the following section.

#### **4.13 God -images among PLWH: Role of belief systems in therapy**

Louw (2008) presents belief systems as having a very great role in the relationships of caregivers and PLWH. Utilization of the God images<sup>91</sup> and specific understanding of these enable caregivers and PLWH and the affected families to react constructively and positively, to live and to adapt in order to cope meaningfully with suffering. The metaphoric<sup>92</sup> presentation or understanding of God by the caregivers and PLWH, as well as the affected families, is important.

Here, it is worth noting that, like other people with various ailments, certain concepts of God are relevant to PLWH with their painful and emotional experiences. They project onto God their needs, frustrations, anger and disappointments. This causes people who endure such experiences to view God in various ways.<sup>93</sup>

On the one hand, infection with HIV raises the difficult spiritual questions that confront most people with life-threatening illnesses. Amongst others: What is life about? Why the pain and suffering? What happens when life ends? Did I bring this upon myself? Do I deserve to be cast out by my family, community or church because of it? Does God still love me?

On the other hand, the stigma associated with HIV has led many people to believe that HIV is a kind of divine punishment for their behaviour by a very angry God who is just waiting for you to

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<sup>91</sup> Louw 2008. *Cura vitae: Illness and the healing of life*, "Appropriate God images denote existential and functional understanding and perceptions about God as related to the basic existential issues. Inappropriate God images can lead to pathology and spiritual illness. In this regard, fixed ideas about morality and law connected to God and his will easily lead to legalism and undue rigour. PLWH and affected families can experience God as withdrawn from them due to their emotional and/or physical pain, placing God at a distance. Then they experience God as uninvolved and disinterested in them. The pain and emotions cause insecurity and suffering and therefore PLWH experience God's absence in their situations. This is not so, because God is present even in the suffering (92-94)).

<sup>92</sup> Metaphors of God can be understood well through the metaphoric monarchical, family, covenantal and theological models. God must be understood as uniquely compassionate, merciful, and tender; caring, involved, intervening, a friend and lover (Louw 2008:93-94).

<sup>93</sup> After suffering and injustice; amongst others, God may be regarded as a tyrant, as a bully because of anger and frustration and as a spoil-sport after disappointment.

mess up then punish you. Given the dilemma HIV people find themselves in, and the strange belief some may exhibit (refer to the above), some people respond<sup>94</sup> in ways that hinder healing.<sup>95</sup>

The way PLWH answer spiritual questions has profound implications for both their physical health and their care-providers. In other words appropriate God images have a lot of implications for PLWH's response (attitude and aptitude) to the issues surrounding the infection, and eventual healing and meaning of life. HRSA (2002:1) noted that there is growing bodies of research showing strong connections between the way people define the meaning of their illness and the strength of their immune systems. Also important is people's ability to cope with illness and loss with the likelihood of them persevering with medical treatment as prescribed.

It is important for the faith and/or spiritual concerns of PLWH and their affected families to be addressed by the spiritual model in pastoral care to help people grow into faith (spiritual) maturity, which will enable them to grasp the connection of the cross<sup>96</sup> and resurrection<sup>97</sup> with their existential reality (Louw:2008:95ff). Particularly when resurrection is contextualized, the lives of PLWH and their affected families will be understood as a power for reconciliation, forgiveness, victory, meaningful embodiment, and healing. This helps them to understand that here God addresses people not just on account of their sin, misery and pain, but deals graciously with his people through victory over death and guilt. This makes life joyful, hopeful and filled with gratitude. This empowerment leads to the spiritual health of PLWH and their affected families.<sup>98</sup> This can be attained if the caregivers take the first step by taking time to understand

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<sup>94</sup> Some people direct their anger to God and caregivers, some refuse to take the medicine - wanting to be miraculously healed by God - whereas others believe HIV is God's punishment for their lives. Hence, taking ARVs to them frustrates God's plans ( HRSA,2002).

<sup>95</sup> In this case, healing refers to the general well-being of a person, that is physical , psychosocial, emotional, and having inner peace (*shalom*).

<sup>96</sup> Here they will then understand that in the cross of Christ, God identifies with human suffering through Christ (compassion and suffering).

<sup>97</sup> This gives hope in the resurrection. Through God's overwhelming power of resurrection, PLWH and affected families have the power and strength to live with dignity and purposefulness, despite the reality of suffering, pain, illness, disability, impairment, death and experience of multiple losses.

<sup>98</sup> In this connection, spiritual health must be understood as implying "a condition of peace ... consisting of a

the needs and the experiences that PLWH and their affected families endure, as will be seen below. This leads us to the section below that will help us have a clear understanding of the needs that infected and affected people have, and how they are connected to spirituality, hence the need for a spiritual approach to care and support.

**Illustration 1: Adapted from De La Porte in Dube (2003), and Louw (2008) -understanding the needs of PLWH and affected families:**

Phases of HIV progression	Emotional responses	Human needs (life needs)	Focus of counseling	Spiritual focus (therapy)
<b>A -symptomatic</b>	<b>Denial, Fear anxiety</b>	<b>Security Affirmation Self-actualization</b>	<b>Empathy</b>	<b>God's compassion Trust</b>
<b>Symptomatic</b>	<b>Isolation, Mourning And loneliness</b>	<b>Connection Intimacy</b>	<b>Communication and relationships</b>	<b>Belonging to a healing community Acceptance</b>
<b>Full-blown Aids</b>	<b>Guilt Remorse Anger</b>	<b>Forgiveness Freedom Deliverance</b>	<b>Restitution</b>	<b>A hopeful and meaningful life (dignity)</b>
<b>Terminal illness and parting tears</b>	<b>Self rejection Depression Hopelessness Worthlessness</b>	<b>Dignity Adaptation</b>	<b>Hope and meaning</b>	<b>Peace (<i>Shalom</i>)</b>
<b>Bereavement</b>	<b>Sadness and longing Anger Depression</b>	<b>Peace and Acceptance</b>	<b>Acceptance of loss, continuing with life</b>	<b>Comforting (courage to be)</b>
<b>Remembrance</b>	<b>Negative memories</b>	<b>Amputation</b>	<b>Living without beloved deceased Investing in life Taking responsibility</b>	<b>Resurrection hope Celebrate life</b>

In this section the study illustrates the importance of a proposed pastoral strategy in the form of spiritual care and support to people living with IV and AIDS .We find below the illustration of

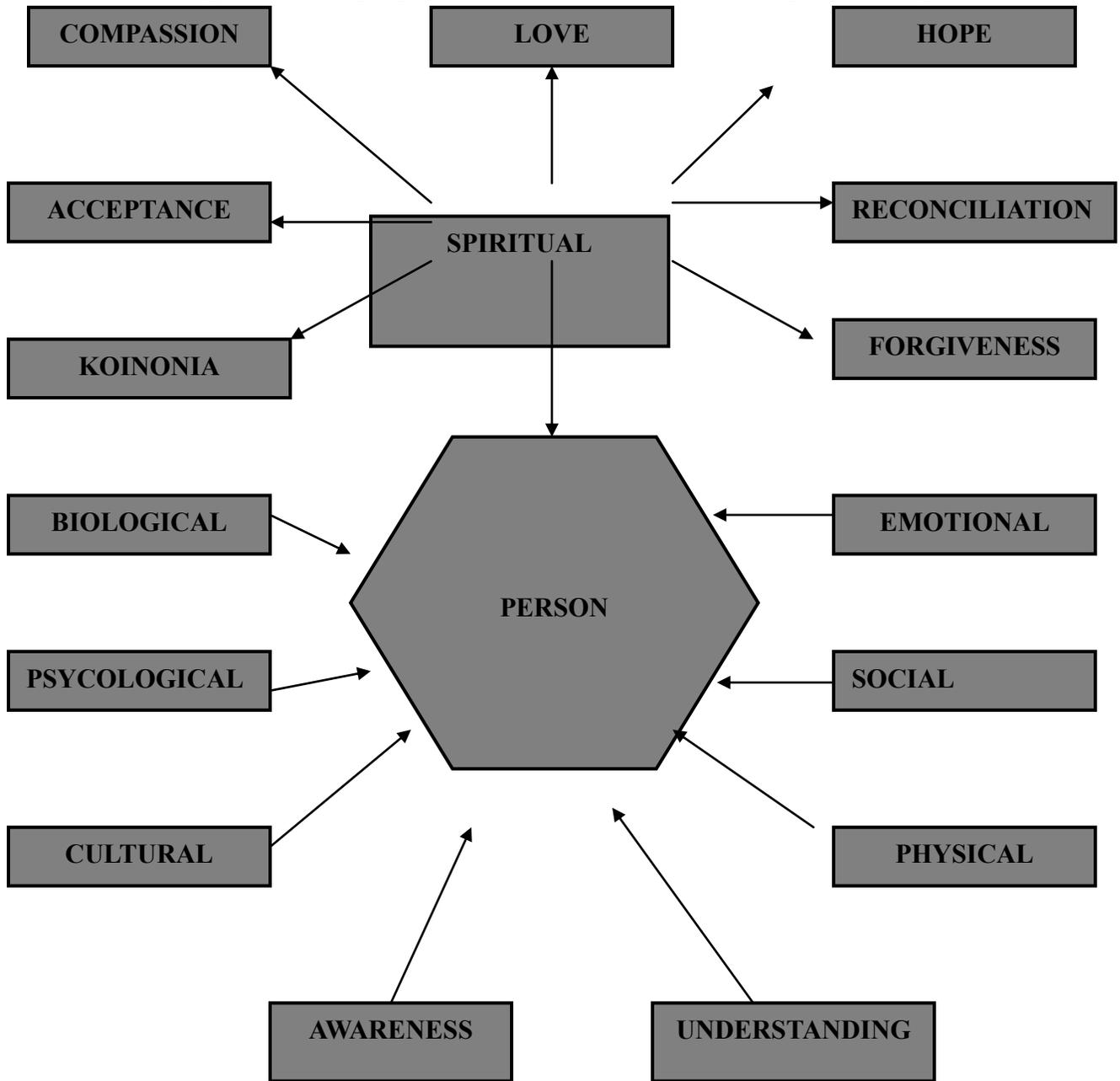
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meaningful life and vitality, spiritual, physical, psychological, social and mundane dimensions of life” (Louw 2008:87). Spiritual healing is also defined as being accepted for who you are without the fear of being rejected.

the model with its major components<sup>99</sup>.

#### 4.14 Spiritual model for the care and Support to PLWH

**Illustration 2:Diagram showing Spiritual Care Model to the care of people living with HIV.**



<sup>99</sup> The component parts of the model are divided into two major parts: the first part revolves around the reality surrounding the person living with HIV and AIDS. This include the psychological, spiritual, social, cultural biological, awareness(information) and understanding of the same. The second part is the outcome of interrelatedness and interconnectedness through the spiritual realm. These are diakonia, koinonia, love, compassion, shalom, hope, forgiveness and reconciliation that enhances human dignity and quality of life and service among PLWH.

The researcher echoes Louw's contributions on spirituality by affirming spirituality that has to do with our being human. This is the type of spirituality that links and integrates a psychological and theological understanding of maturity. Vital to this linkage is human relationships, which means spirituality can be truly experienced within the context of human relationships (2008:53 quoted from Richards (1987:244). The illustration above is a spiritual model proposed by the researcher as suitable for effective care and support of PLWH in Plateau hospital.

Through the spiritual care model, caregivers are aware of all the factors influencing the needs of those cared for (PLWH). These factors inform the understanding of the caregivers, and the appropriateness of the decision making and choice of support for those cared for. The ultimate aim of the understanding PLWH' needs within the spiritual model is, clarity on what needs to be done, quality of the support and meaning making that PLWH and the affected people get within interactions in the therapeutic space.

In the illustration above, the care of people living with HIV has to take into consideration eight aspects of the person. These aspects are all important for the infected (PLWH) or affected persons. The holistic healing could be realized only if the following aspects are all taken into consideration: empathic understanding, awareness of the context, cultural, physical, social, psychological, biological, and spiritual aspects. The researcher is convinced that, when all of the above have been fulfilled, the PLWH or the affected family or community will experience acceptance, unconditional love, find meaning, forgiveness, reconciliation and future hope beyond suffering and pain.

The following section will shed more light on how some of the selected aspects work within the pastoral approach by means of spiritual care.

**Compassion:** Compassion in the care and support of PLWH is more than a gut-level reaction in response to another person's needs. It calls for understanding, penetrating to the root of the misery and being moved to act in order to do something to improve the condition of the affected person (De la Porte in Dube (2003) HIV/AIDS: Curriculum).

**Empathy:** In the context of care and support of PLWH, “empathy” refers to considering the other person's feelings and situation through his/her frame of reference and communicating this understanding to him/her. Empathetic understanding in the context of HIV is a prerequisite for caring. This entails gaining insight into, and an understanding of, the plight of the person who has been diagnosed HIV positive. Other than the individual caregiver (spiritual carer), support groups could be formed in order to relate with and communicate empathy and compassion to the PLWH and the affected families.

This will also enable the carers to understand the person’s emotional, social and spiritual needs, which then will help them to come to grips with their own mortality and terminal illness.

**Hope, security and compassion:** With hope and compassion, the carers also assist PLWH to use their spiritual resources to generate hope and meaning in life (Dube: 2003:131). Furthermore, it will also enable them to help families of PLWH to cope with the stress of caring for this terminally ill person. By means of spiritual guidance, the carers provide the support needed during bereavement.

Concerning the security of PLWH and God's compassion, it is important for caregivers to identify the role of security and God's compassion in their own lives so that they may better understand these needs in PLWH and, therefore, understand the connection built on trust and the experience of security. It is further important for the caregivers to communicate these aspects of security and compassion to the PLWH, their families and other caregivers. This can be realized by compassion (MAP: 1996:9), acts of mercy, group visits, the congregation’s and the pastor’s pastoral care,<sup>100</sup> and the scriptural assurance<sup>101</sup> of God's presence<sup>102</sup> and protection.

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<sup>100</sup> Through pastoral care, the caregivers can communicate and verbalize the dimension of meaning and the comfort of the Gospel in such a way that the people are consoled, hopeful and empowered and also comforted in their being functions.

<sup>101</sup> Ps 23, Joh 8:1-11, Mat 9:9-13, Ps 118:5-8, Heb 13:5a-6, Rom 8:31-39, Deut 10:17-21, Heb 4:12-14, Joh 10, Ps.91.

<sup>102</sup> Through pastoral care embodiment and enfleshment, engagements of God with life issues of PLWH are such that actions of comfort, change and liberation - transformation taking place - is a vivid presence of God (Louw

**Koinonia:** Communicating connection in the process of spiritual care concerns the caregivers' understanding of how to create a sense of community and connection in their work – a sense of *koinonia*.<sup>103</sup> This is therapeutic for people who feel disconnected from their families, communities and work places due to the HIV infection and the stigma that results from it. Improved relationships will go a long way in promoting acceptance, hence realization of therapy in the process.

The study envisions that through spiritual care, caregivers will have an opportunity to share the good news of the gospel of Jesus Christ with PLWH and the affected families. This will facilitate sharing of messages of release, unconditional and sacrificial love, eschatological hope, and God's being in identification with PLWH and affected families. This will then act as motivation for all medical and non-medical caregivers in Plateau Hospital to emulate Jesus Christ's ministry through CBHC.

Through the reconciling<sup>104</sup> function of pastoral care, caregivers could help PLWH who are struggling with broken relationships, so as to overcome estrangement, isolation and hatred. By means of this, forgiveness will be facilitated between PLWH and the self, colleagues, the family, the community and God.

Other practical intervention strategies that are relevant to the spiritual perspective on the care and support of PLWH, OVC, those affected and carers, include:

- Grief and bereavement counseling: this helps the infected and affected experiencing grief to deal with the loss of control and of loved ones so that they may face life positively.
- Listening to and helping the affected families and the infected in times of need.
- Recognition and acknowledgment of orphaned children's total needs.
- Involving children and affected families in decision-making, and also enabling children to live as children and grow up.
- Providing opportunities for spiritual care for all vulnerable groups.

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2008).

<sup>103</sup> Louw, DJ. 2008. *Cura vitae: Illness and the healing of life: A guide for caregivers*. Wellington: Lux Verbi.

- Sensitizing the community to the situation in which PLWH and OVC are living so that stigma and discrimination may be reduced through unconditional love, acceptance and compassion.
- Sensitizing the community and church leaders to help demystify HIV and AIDS causes, for instance, how HIV is not transmitted or is transmitted.
- Encourage religious leaders to be role models for their religious groups – by visiting those infected and affected with HIV, and challenging their members to emulate Jesus' healing ministry.
- Build support networks of HIV activists, and 'significant other' support networks for children.
- Treating PLWH with dignity.

The approach of spiritual care attempts to influence the atmosphere of serving and caring within the community - whether institutionalized or home-based - from the stigmatizing, negative responses to PLWH, which lead to fear, isolation and despair (hopelessness), to a more positive, unconditionally loving, accepting and understanding response that could lead to change through quality of service, life, and eventual healing<sup>105</sup> (*shalom*). Through this approach to care of PLWH, healing of the infected, affected, caregivers and communities will be experienced. The church (RCEA) is well placed to ensure realization of shalom among PLWH and the affected families and communities through her various ministries (e.g. the underutilized Chaplaincy office at Plateau, diaconal ministries in each local congregation, women and youth ministries in RCEA parishes).

#### **4.15 The church and ministry to PLWH**

Map International (1996:2-5) has observed that the church has a great responsibility in reaching out to all people whatever their situation. Map continues that AIDS is not only a medical problem but also a spiritual and social issue with which Christian leaders and their laity must involve themselves, and be committed to address HIV/AIDS related issues. For the church to do

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<sup>104</sup> Louw 1994. *Pastoral hermeneutics of care and encounter*. Cape Town: Lux Verbi.

<sup>105</sup> This is the real healing (spiritual), which Louw calls “healing of the human soul.” And, for this healing to occur, it must have interconnectedness and interrelatedness within which the person experiences intimacy – where PLWH are accepted for who they are without the fear of ever being rejected.

this, it needs to mobilize its members for involvement in helping PLWH, and those not infected to remain uninfected, and at the same time caring for and supporting PLWH, orphans and vulnerable children and widows affected by the pandemic.

The presence of HIV/AIDS is a wakeup call to the church to reclaim her identity as the church of Christ called to follow the example of her master Jesus Christ. If the church does this, the researcher is convinced that healing, restoration, self and sacrificial love will be exercised. This will foster reconciliation of PLWH and the affected to themselves, the world and their creator. In the long run, God's `grace, resurrection hope, salvation<sup>106</sup>, changed feelings and attitudes<sup>107</sup> pastoral<sup>108</sup>, priestly<sup>109</sup> and prophetic<sup>110</sup> roles will be exercised and communicated by congregations to the affected, infected and the caretakers in Plateau.

With a picture of the effects of HIV stigma in mind, the researcher sees Plateau congregations as the communities of origin of PLWH. Based on the experiences of PLWH, the researcher challenges RCEA to consider what the Lutheran World Federation observed as the involvement of the church in HIV ministry:

“The church is bound to counter culture by including those who are excluded from society. It is here among the stigmatized that the crucified God is found. We meet the resurrected Christ in the breaking of the bread and are transformed into communion. We become one with those whom others might consider unclean, dangerous or scandalous. Through baptism, we become part of the body of Christ. We belong intimately to Christ and thus to one another as brothers and sisters in Christ. Whether we are living with and affected by HIV and AIDS or not, we belong to the same communion..... Christ is present for us in the communion; we are called to be present with those who are infected and affected by HIV and AIDS” (2007:9)

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<sup>106</sup> Louw (2008)

<sup>107</sup> These entail feelings of self-righteousness, judgmental attitudes and faulty church doctrines.

<sup>108</sup> To meet people where they are and to identify with them during their times of needs.

<sup>109</sup> To be the mediators and intercessors on behalf of God's people before God's presence.

<sup>110</sup> Be aware of the dangers HIV poses to humanity, warn people of consequences of irresponsibility and proclaim salvation.

The Lutheran World Federation (LWF) has further observed that *diakonia* is part of the very being of the body of Christ. It is the church's body language, how it bears witness in the world: compassionately reaching out to be with and serve all those who are suffering, especially those living and affected by HIV and AIDS, and advocating with, and for, them.

To the LWF, Christ's unconditional love is the true spirit of *diakonia* - living with, walking with, touching, understanding, sharing, caring and struggling alongside. But churches hesitate to do this in the face of AIDS. Instead of becoming part of the solution to the many challenges that PLWH face, they are often part of the problem, especially when their attitudes and practices stigmatize and exclude those who are affected and infected. It is pathetic that local congregations are often places where PLWH feel most excluded, stigmatized or unwelcome. Sometimes they are denied holy communion, or drinking from the communion cup (Lutheran World Federation:2007: p.9H)The church should be a place for spiritual support and social healing, where hope for the future is proclaimed and lived out.

In *Illness and crisis as challenge*, Louw (1994) confirms the position of the LWF as follows:

“The church must also begin a buddy model which means gathering HIV patients into groups in which they must be encouraged to become involved with society and their education processes. They must also be encouraged to start care groups, which could take over their basic care during their terminal state. On the diaconia level, the church will have to educate support and aid groups with a view of caring for AIDS patients in the vicinity or area ... that AIDS becomes an opportunity to demonstrate anew the authenticity of the church's charitable service and the credibility of Christian neighbourly love” (p.134).

#### **4.16: Concluding remarks**

In this chapter the researcher discussed HIV/AIDS as a challenge to spiritual care: The Quest for meaning and dignity. The paper presented the effects of HIV on PLWH and the affected families as silence, stigma and discrimination in Plateau. The paper showed that HIV/AIDS presents enormous challenges to the individual, communities, society, and institutions or organizations, and this poses questions on how spirituality should be integrated in the ministry to people living

with HIV.<sup>111</sup> .

The study noted that, due to stigma and discrimination, PLWH and affected families face rejection, guilt, fear, and secrecy for survival, loss of hope, hatred, loneliness, and loss of dignity. In our view, this calls for the need of understanding and integrating the intervention approaches to meet all needs, so as to enhance the quality of service to, and life of, PLWH and their affected families.

The chapter also noted some of the attitudes, reactions and services of individuals and service providers that affect PLWH and, instead of promoting health, affect their health negatively, for instance, secrecy for survival, depression, and early deaths, just to mention a few.

When examining health care systems, the study established that, in health care, the biomedical model has dominated the field of care but, with time, health practitioners noted the inadequacies (interest in pathology), and started to promote the bio-psycho-social approach, which addresses biological, social and psychological health needs (more interest in health than in illness). Still, both approaches are divisive, as they are interested in the body, and separate the person from the illness and the social and environmental support systems.

The study also shows that there are more than bio-psycho-social aspects to life. This insight has led to the development of the systemic approach. This approach recognizes the need to regard people as social and relational human beings within a specific context. However, the biomedical and bio-psycho-social approaches still use the interpretation and diagnostic approaches that treat the human being like a machine with parts, some of which can be taken out and studied. We also saw that a new understanding in the medical field underscored the holistic approach by recognizing that a person comprises the physical, social and spiritual components, therefore emphasizing the need to attend to the spiritual needs as well. This, however, calls for proper integration of spirituality in an age-old field still influencing care-giving. The new medical understanding underscores the centrality of spiritual care of PLWH. The basis for this was made clear by examining the spiritual care of PLWH, which promotes a holistic approach to care for

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<sup>111</sup> CBHC and PLWH report on interview responses from the Plateau Mission Hospital.

these people.

For the Plateau Hospital to implement the holistic systemic spiritual care of PLWH, attention has to be given to pastoral theology, pastoral care disciplines and the use of appropriate God-Images as these were seen to be avenues through which de-stigmatization and affirmation of human dignity could take place in therapy.

Through the spiritual model of care, PLWH experience unconditional acceptance and love, compassionate care, the being functions of the caregiver, the participation of all stakeholders, being treated with dignity, understanding, and having their support systems strengthened. Also important are listening, sharing, hope for resurrection, communication, helping and the holistic healing of the person and systems. Through the spiritual model, the person's physical, biological, social, cultural, psychological and spiritual components are taken into consideration. And through this interconnectedness, healing of the soul is realized in *shalom*. The study sees the ultimate goal as: the realization of freedom and hope, strengthened support systems through koinonia, life fulfillment through diaconia, experience of the Grace of God, quality of new life with understanding, and sacramental experience, all of which expel the existential issues of anxiety, guilt, anger and frustration among PLWH, the affected families and wounded communities. Finally, we have also seen that the church forms the core-healing unit in a wounded community and for RCEA to be relevant in the context of the CBHC experience, it is time that it consider adopting a participatory approach to ministry to people living with HIV. And through diaconia, grace, mercy, love and salvation from God would be shared in the congregations and community from where the PLWH are.

In the following chapter the study will describe the findings of the field study on the care of PLWH and affected families in Plateau. To be taken into consideration are the unmet needs of PLWH, people involved in the care programme, and how pastoral care through the spiritual model could help improve the quality of care in Plateau Hospital's CBHC programme. Lessons learnt and recommendations will be found at the end of the chapter.

## **CHAPTER 5: CONCLUSIONS AND RECOMMENDATION**

### **5.1 Conclusion**

This study was based on the hypothesis that, due to the dominance of the medical approach in response to people living with HIV, some deep-felt needs of PLWH, such as spiritual needs, are seldom met, and a pastoral approach in a holistic model for the care and support of PLWH is therefore of great importance. A spiritual approach to the care of these people should supplement the medical model in order to provide a more holistic team approach.

The main questions with which the study grappled were:

1. What types of spiritual needs of PLWH are met/not met by the care and support that the Plateau Mission Hospital's CBHC programme renders? and
2. What are some of the gaps and key stumbling blocks in the current strategy that the Plateau Mission Hospital implements in the care and support of PLWH that would require evaluation and integration in order to enhance the quality of care?

The outcome of this study has revealed the effects of a dualistic approach to the healing of a person, based on either body or soul. It calls into question the purely medical model, which uses the clinical approach of presentation and diagnosis and the study of only some aspects of a person (divisive).

The study also revealed that compassionate care was overlooked by the community and the church which then thwarted the efforts of the medical team in implementing the psycho-social support. At the same time the exclusive medical approach used by Plateau hospital left other key players out and this increased stigmatization of PLWH and affected families. However, there is hope of positive change. Communities, congregations and leaders have realized the need for use

of an approach that will ensure the goals and aims of CBHC are achieved. The researcher saw a change of feelings and attitudes, taking ownership of owning up intervention strategies and a willingness to shift positions as indicators of easing the uphill task of PLWH care in the past five years.

It is the right time for the biomedical and bio-psycho-social models towards health to consider critically the neglected but significant aspects of health care that will lead to the care of the whole person, particularly for PLWH and their affected families. The spiritual approach realizes therapeutic space, through which the needed help is easily channeled to PLWH and the affected persons because this approach brings about a change of position in therapy. The study showed that the hospital had acknowledged the need to adjust its initial care plans of prevention, treatment and material and psychological support, to include aspects of compassion, love, being functions, humane treatment of PLWH with dignity and faith maturity, which are provided by the spiritual model for care and support to PLWH.

This further challenges the implementer of health care programmes at the Medical Hospital to consider the spirituality of all people, irrespective of their religious affiliation, as this is an important and vital component of healing. This means going beyond the psychological, social, or biological aspects in healing.

For the medical care to be effective in the provision of care and support within a given area, there is a need for greater partnership with key players in the care and support system. This will call for the adoption of a participatory approach, and realization of this could come about through the koinonic aspect of spiritual care where all key stakeholders voluntarily share in the care and support of PLWH. The functioning of a systems approach where PLWH, communities, leaders in the community, the affected, medical personnel, volunteer caregivers and spiritual leaders are linked for a better understanding of the existential realities that affect the infected and affected will lead to taking of appropriate measures in addressing PLWH and affected people's needs. Hospitals no longer have the excuse of only using technology, and considering the biological, psychological and social aspects in healing. For them to offer care to the whole person, the spiritual component is key in delivering holistic care to PLWH. This calls for an interdisciplinary

approach where spiritual leaders could play a part in the care of the whole person.

The spiritual care approach aims at promoting a clear understanding of the needs of PLWH and the affected families within a medical system of care that is linked to other systems, families, communities and congregations. The researcher is convinced that a proper understanding of PLWH needs will enhance effective intervention strategies, both short- and long-term for individuals and groups. Based on the systems approach, a spiritual approach pastoral dimension employs the principle of collaboration with the intention of promoting holistic healing to infected persons, affected families, caregivers and communities.

A spiritual approach's pastoral dimension in the care of PLWH and affected people also aims at building sustainable support systems accessible to these people. These will be safe spaces where unconditional acceptance and listening with love, empathetic understanding, the valuing of human dignity, compassionate care, being functions, forgiveness and reconciliation and resurrection hope are nurtured. This will put the approach within the holistic healing perspective for relevance contextuality.

Eventually, by means of the spiritual model, families who cannot support and care for their ill loved one because they are depressed and scared due to the stigma associated with HIV, will find it easier to work through loneliness, anxiety, and depression that worsen their patient's illness and make them vulnerable when their immune systems are low. Better still, community networks would support the families of PLWH. The approach will also promote community activists who will ensure the formation of activist groups for coping, as well as support groups that will provide a safe space for the sharing of experiences.

## **5.2 RECOMMENDATIONS**

### **5.2.1 The implementation of a spiritual model**

The spiritual model at the Plateau Hospital will go a long way towards speeding up efforts geared towards comforting and attaining meaning in suffering, promoting holistic healing and instilling hope in PLWH and infected communities. The formation of support groups, establishing advocates within the support groups, training all caregivers on the components of

spiritual care, understanding the needs of the infected and affected, understanding the God-images irrespective of the PLWH and affected families' religious inclinations, and addressing existential realities within specific contexts will ensure that CBHC works towards improving the quality of service and quality of life of the CBHC clients.

It is hoped that the study will be instrumental in the improvement of the quality of care, support and lives of PLWH and the affected families in Plateau.

### **5.2.2 Streamlining Hospital Chaplaincy for spiritual care**

The researcher observed that there is need for improvement and strengthening of Chaplaincy at the hospital, which was observed to be underutilized. This would go a long way to building a stronger team. This will include hiring or getting more volunteers to work alongside the one chaplain, assigning different people different chaplaincy roles: some for hospital ward spiritual care, a general prayer coordinator, a staff spiritual carer, a community spiritual carer, and an RCEA Plateau High School spiritual leader. It is hoped that this will increase efficiency and quality of care for the entire hospital community.

### **5.2.3 Further research**

The researcher has observed that the culture of silence and fear within the communities causes stigma and discrimination in Plateau. These are fueled by the cultural and social factors in the community. These are important aspects to be addressed since they promote the stigmatization attached to HIV and increase the suffering among the infected and affected. Since the areas require in-depth study (which was impossible in this study) on how these aspects affect the care and support of PLWH and affected families, the researcher therefore proposes further study in social cultural factors that hamper the care and support of PLWH in Plateau, with special reference to alcohol, sex and sexuality among the Kalenjin people in the Plateau community. These factors, as observed by the researcher, lead to the vulnerability of girls women, and families in the face of HIV, and need urgent attention.

### **5.2.4 Appeal**

Last but not least, the researcher is equally convinced that the RCEA has great potential to attain a systems approach to realize spiritual care for the infected and affected members of the

community. The holistic mission and collaboration within the structures of the RCEA are her strength and, based on this and the willingness of the Plateau Hospital to allow more participants into the care of PLWH and affected families, the researcher therefore recommends that the national office of the RCEA, in all her ministries, takes on the challenge of promoting holistic care through a spiritual model for PLWH and the affected. This should include theological training of pastors, Christian education, women, the youth and children and diaconal ministries and leadership training. The researcher is also convinced that, through the National HIV/AIDS Care office, it is possible to implement a spiritual care model that will be affected through all RCEA structures: committees, local congregations, parishes, presbyteries, and the Synod. The researcher contends that when this is done, the RCEA will not only be fulfilling her calling, but the holistic mission of her ministry strategy in the Plateau community and in East Africa as a whole. And for more relevance to RCEA Plateau Hospital CBHC programme, strengthening the structure by bringing in more people to work as volunteers alongside the main chaplain will serve the spiritual needs of the staff, terminal clients in their homes and the community, outpatients who come to the hospital, inpatients in wards, and RCEA Plateau high and primary schools.

## **APPENDIXES**

APPENDIX 1 Map 1-Map of Kenya

APPENDIX 2 Map 2-Map of Uasin Gishu District

APPENDIX 3 The RCEA's organizational structure

APPENDIX 4 The RCEA's CBHC organizational structure

APPENDIX 5 Case study 1-Joses-Compromised Dignity

APPENDIX 6 Case study 2-Jully-Anger , Frustration

APPENDIX 7 Case Study3-Adelide-Rejections

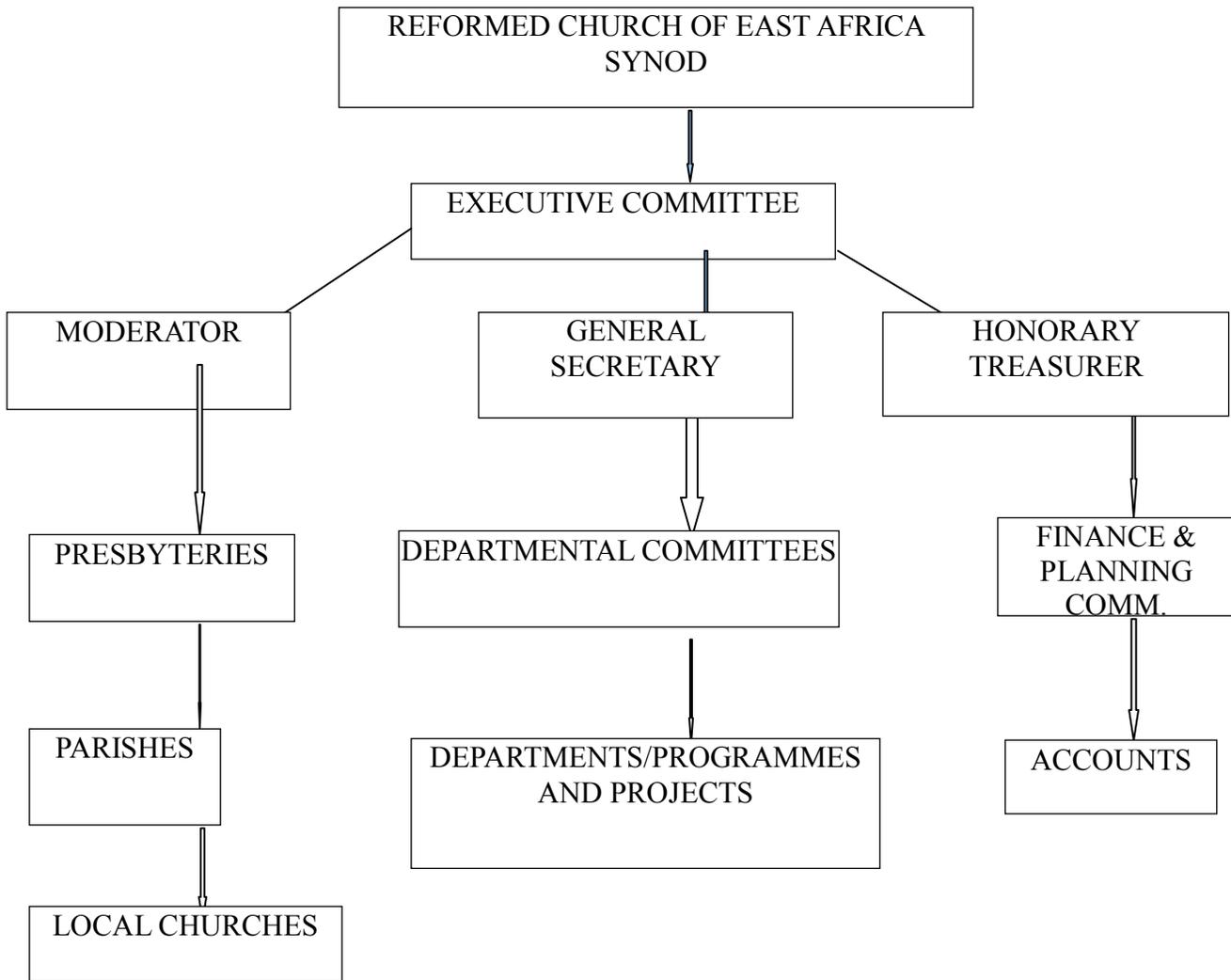
APPENDIX 8 CBHC questionnaires

APPENDIX 1: MAP 1-Map of Kenya showing all the districts: bushdrums. 2006

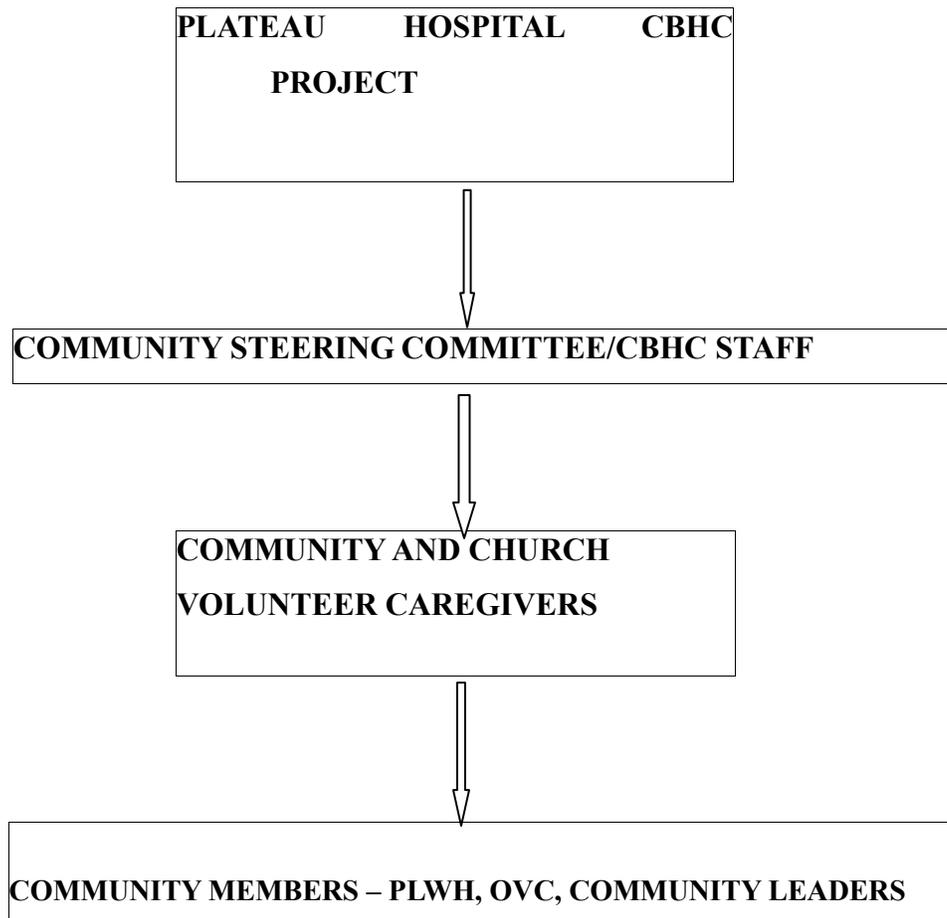




**APPENDIX 3: THE RCEA'S ORGANIZATIONAL STRUCTURE**



**APPENDIX 4: ORGANIZATION AND PROJECT STRUCTURE:- PLATEAU HOSPITAL CBHC**



## APPENDIX 5: COMPROMISED DIGNITY: CASE STUDY 1: JOSES

Joses was diagnosed with HIV in 2005.

He suffered a lot of discrimination in the larger family. This affected him so much that later that same year, Joses died.

The family was not willing to pay him his last respects. Instead they called the health facility that was treating him to come and take him away since they regarded him as an outsider and one who did not deserve the funeral rites and rituals in the family.

After a discussion, Joses was finally laid to rest. Everything he used while he was sick, his plates, clothes, bedding and bed, were burnt and thrown away immediately after his burial.

## **APPENDIX 6: CASE STUDY 2: -FRUSTRATION, ANGER AND DESPAIR**

At the age of only 13, Jully lost both his parents through HIV. His father died in October 2003, whereas his mother died in March 2004. Being the only child, he did not have someone to stay with. His uncle took him for a few months, but could no longer stay with him. Jully was so frustrated. He could not understand why his parents had died. He was angry with his uncle and grandfather who were staying with him. He was angry with God for the death of his parents and had no hope. He later turned his anger against himself. He went into total isolation and finally wanted to commit suicide but was rescued by good Samaritans.

## APPENDIX 7: CASE STUDY 3: - ADELIDE'S REJECTION

Adelide's husband was diagnosed with HIV in 2000.

He stayed in denial for one year. Towards the end of 2001, he became so sick that he was hospitalized.

Adelide's husband grew very weak and in March 2002 he passed away leaving her pregnant with their baby.

Soon after the burial, the family of the deceased told Adelide to collect all her clothes and go away for they believed she had brought the disease upon their son.

They took away all her property, sold all the cars and told her to return to her parents' home. Adelide had to leave.

## APPENDIX 8: CBHC STAFF/PLWH/CONGREGATION QUESTIONNAIRE

**Name of Interviewer**.....

**Date**.....**Time**.....

**Name of Respondent**.....

**Position/Religion/Location**.....

### **The role Plateau Hospital CBHC in care to PLWH**

1. How has the CBHC programme/ staff responded to the HIV pandemic in Plateau?
2. To what extent has the Hospital's HIV/AIDS work impacted on other spiritual issues in the community of Plateau?
3. How else could CBHC respond to the needs of PLWH?

### **How needs of PLWH in Plateau Hospital catchment area are met**

4. How are the needs of PLWH met in the CBHC programme?
5. What needs of PLWH are not met by the Hospital support groups?

### **Perspectives on pastoral and spiritual care to PLWH**

6. How else could pastoral and spiritual care help in the support of PLWH?
7. What qualities of pastoral and spiritual care and counseling are needed?
8. Who are involved in the pastoral care of people living with PLWH?
9. What would be expected of pastoral and spiritual caregivers in Plateau?
10. Which spiritual resources are used in the care of PLWH?

### **Questions on participatory care and support to PLWH in Plateau**

11. Who else should be involved in the care and support of PLWH in Plateau?
12. What is the level of the programme participation in HIV work?

### **Issues of stigmatization among PLWH**

13. How free are clients to disclose their HIV status?

14.How often do client come for support?

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