

**COMMUNITY HOME BASED CARE
FOR PEOPLE LIVING WITH HIV /
AIDS IN THE GOODHOPE SUB-
DISTRICT:BOTSWANA.**

***POLICY PLANNING AND
IMPLEMENTATION.***

BY

SEBOKWANE DIKGOPE

SUPERVISOR: DR.S. GEYEVU.

**SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS OF A DEGREE OF MASTER OF ARTS IN
THE DEPARTMENT OF SOCIAL POLICY, UNIVERSITY OF
DURBAN-WESTVILLE, DURBAN. SOUTH AFRICA.**

DECLARATION

I declare that THE COMMUNITY HOME BASED CARE FOR PEOPLE LIVING WITH HIV \ AIDS, THE CASE OF GOODHOPE-BOTSWANA: POLICY PLANNING AND IMPLEMENTATION is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

.....
S. DIKGOPE
JUNE 2003

DEDICATION

TO MY FAMILY MEMBERS WHOSE LOVE AND SUPPORT HAVE SEEN ME THROUGH OUT MY STUDIES. SPECIAL DEDICATION TO MY BELOVED SON (KEFILWE VULA DIKGOPE) WHO WAS VERY SUPPORTIVE IN EVERY WAY TO MAKE MY STUDIES A SUCCESS. TO HIM I SAY "KEEP UP THE SPIRIT, YOU ARE A STAR ".

ACKNOWLEDGEMENT.

My special gratitude goes to the supervisors of my thesis, Prof. D. Hindson and Dr. Sam Geyevu whose continued guidance and support has seen me throughout my period of writing the thesis. To Dr. Geyevu, thank you so much for the fatherly love you have given me throughout my stay in South Africa otherwise I could not have made it.

I owe my thanks to Academics at the University of Botswana, especially Prof. K. Osei-Hwedie and Prof. L.K. Mwansa for having been so much helpful in providing me with the necessary literature.

To my special friend Prof. P. Mufune, I say, "you made me proud by all the encouragement you gave me to pursue a Masters course, keep up the spirit."

Within the Social Policy Programme, Prof. Priya was very helpful, thank you for the warm heart and motherly advices you have given me. Special attention goes to Emmanuel Odei Oduro for the good company and support he has given me throughout my studies.

A big thank you to the many relatives and friends who contributed positively to making my studies a success

Finally, thank you God for having made it happen.

My special acknowledgement goes to the Canon Collins Educational Trust For Southern Africa for having sponsored me throughout my studies.

ACKNOWLEDGEMENT.

My special gratitude goes to the supervisors of my thesis, Prof. D. Hindson and Dr. Sam Geyevu whose continued guidance and support has seen me throughout my period of writing the thesis. To Dr. Geyevu, thank you so much for the fatherly love you have given me throughout my stay in South Africa otherwise I could not have made it.

I owe my thanks to Academics at the University of Botswana, especially Prof. K. Osei-Hwedie and Prof. L.K. Mwansa for having been so much helpful in providing me with the necessary literature.

To my special friend Prof. P. Mufune, I say, "you made me proud by all the encouragement you gave me to pursue a Masters course, keep up the spirit."

Within the Social Policy Programme, Prof. Priya was very helpful, thank you for the warm heart and motherly advices you have given me. Special attention goes to Emmanuel Odei Oduro for the good company and support he has given me throughout my studies.

A big thank you to the many relatives and friends who contributed positively to making my studies a success

Finally, thank you God for having made it happen.

My special acknowledgement goes to the Canon Collins Educational Trust For Southern Africa for having sponsored me throughout my studies.

Opinions expressed and conclusions drawn are those of the researcher and should not necessarily be attributed to the above-mentioned sponsor.

ABSTRACT

Botswana occupies an unenviable position of having the highest HIV / AIDS infection rate in the world, and this has generated pressures on health facilities as they are over stretched beyond their coping capacities to attend to the ever-increasing numbers of people who are infected. To relieve the health care system, the Botswana government has adopted the CHBC programme as an instrument for taking care of the infected and affected people. The CHBC programme, which is care given to long term and terminally ill people adopts the approach that, the family and the community assisted by the health professionals are the primary source of support and care. CHBC has always been in existence, though it was not given the attention it deserves until the realities of HIV / AIDS pandemic struck and doubted the ability of the health facilities to accommodate the ever increasing HIV / AIDS cases.

CHBC gained more support as a result of the HIV / AIDS pandemic. This is the case because of the programmes' rationale that, the home is the best place to care for many of the people with terminal illness. The programme gives patients chance to be looked after in a familiar environment and by their relatives.

The aim of this study is to establish the existence of a CHBC Policy in the Good hope Sub-district in Botswana, and if it exists to find out whether implementation is congruent to the Policy guidelines, whether its implementation is done in the most effective way, and if not, to identify obstacles to effective implementation of the Policy in the Goodhope Sub-district. The hypothesis of this study is that, CHBC for people living with HIV / AIDS is ineffective in the Good hope Sub-district of Botswana because of shortage of resources, the unexpected (low) support the Programme gets from the community and the incorrect understanding of HIV / AIDS issues especially the modes of transmission by the community. The sample used consisted of 57 research participants (10 HIV / AIDS patients, 10 care-givers, 10 Policy makers, 10 health professionals, 5 traditional doctors, 5 spiritual healers, 5 village headmen, 1 village chief and 1 NGO representative).

The literate respondents were given structured questionnaires to complete while those who are illiterate were helped by the researcher to fill in the questionnaires. The focus group discussion and participant observation methods of data collection were engaged. The study's findings were that, the

CHBC Policy does exist in the Good hope Sub-district of Botswana. The study further discovered that, implementation of the Policy is not as effective as expected, and this has been attributed to the following problems; shortage of resources (manpower, transport, food etc) and the community's reluctance to give it support.

The study recommends that, the government should provide resources to train more professionals who would address the problem of manpower inadequacies. There is need for communities to be mobilised so that they join hands in the fight against HIV / AIDS. The Government has to see to it that enough resources are allocated to the CHBC Programme. There is need for HIV / AIDS education in order to equip the community with the necessary information on HIV / AIDS issues. All caregivers need to be given relevant training on HIV / AIDS issues. Lastly there is need for further research in this field in order to find better ways of improving CHBC Programme.

LIST OF TABLES AND FIGURES

Table 1	7
Table 2	10
Table 3	11
Table 4	13
Table 5	14
Table 6	19

TABLE OF CONTENTS

	PAGES
i. DEDICATION	
ii. ACKNOWLEDGEMENT	
iii. ABSTRACT	
iv. LIST OF TABLES AND FIGURES	
1 CHAPTER ONE: INTRODUCTION	1
1.1 Statement of the problem	1
1.2 Hypotheses of the study	1
1.3 Definitions of concepts	2
1.4 Specific objectives of the study	3
1.5 Significance of the study	3
1.6 Background information on HIV / AIDS	4
1.7 The HIV / AIDS Policy in Botswana	5
1.7.1 The overall strategy of the HIV / AIDS Policy	6
1.8 The CHBC Programme in Botswana	7
1.8.1 The rationale of the CHBC Programme	8
1.8.2 The CHBC Programmes' objectives	9
1.8.3 The merits of the CHBC Programme	9
1.9 The summary of the CHBC Programme	10
1.10 Structure of the Thesis	11

1.11	Summary	12
2.	CHAPTER TWO: LITERITURE REVIEW	
2.1	Introduction	13
2.2	An International perspective on HIV / AIDS	14
2.3	The African perspective on HIV / AIDS	14
2.3.1	Factors influencing the impact of the HIV / AIDS epidemic in Africa	15
i.	Economic factors	15
ii.	Infrastructural factors	16
iii.	Socio-cultural factors	16
2.3.2	Costs of the HIV / AIDS in Africa	17
i.	Socio-economic factors	17
ii.	The human costs of the HIV / AIDS epidemic	17
iii.	The social costs of HIV AIDS epidemic	18
iv.	The economic costs of the HIV / AIDS	18
v.	The indirect economic costs of the HIV / AIDS	19
2.4	The United Nations response to the HIV / AIDS epidemic	20
2.4.1	The UNAIDS mission (operations)	21
2.5	The Botswana perspective on HIV / AIDS	21
2.5.1	Factors contributing to the rapid spread of the HIV / AIDS	22
2.5.2	Reactions of different groups towards HIV / AIDS	22
2.5.3	Workers in the Health settings	24
2.6	Conceptual framework guiding the study (the community Partnership, the network approach)	25

2.7	Distinctive roles played by various service providers to the HIV / AIDS patients	27
	i. Formal service providers	27
	ii. Informal service providers	28
2.7.2	Applicability of the model to the CHBC Programme	29
2.8	An overview of CHBC	31
2.8.1	A look at the African CHBC Programme for people living with HIV/AIDS:(Zimbabwe (Zinatha and Chirumhanzu CHBC projects)	33
2.8.2	A Tanzanian model (Kilimanjaro and Wamata CHBC projects	38
2.10	The Botswana model	40
2.10.1	Definition of CHBC	42
2.10.2	CHBC rationale goals and specific objectives	43
2.10.3	CHBC proposed team	45
2.10.4	Recommendations on CHBC	45
2.11.1	The case of Goodhope (study area)	46
2.11.2	Common elements with CHBC projects	47
2.12	Needs of the HIV / AIDS patients	47
2.12.1	CHBC programmes' advantages	51
2.12.2	CHBC disadvantages	53
2.13	Summary	55

3. CHAPTER THREE: RESEARCH METHODOLOGY

3.1	Introduction	56
3.2	The qualitative research paradigm	56
3.3	The study population	58

3.4	Sampling and sampling size	59
3.4.1	Sampling and accessing participants	60
3.5	The study setting	61
3.6	Data collection	62
3.6.1	Pilot study	62
3.6.2	Instrument for data collection	63
3.6.3	Participant observation	64
3.6.4	Researchers' observation	65
3.7	Data analysis	66
3.8	Ethical considerations	66
3.8.1	Potential psychosocial consequences of research interview	67
3.9	Dissemination of research findings	68
3.10	Limitations of the study	68
3.11	Summary	69
4	CHAPTER FOUR: DATA ANALYSIS	
4.1	Introduction	71
4.2	The HIV / AIDS patients and caregivers' views on HIV / AIDS	71
4.3	The HIV / AIDS patients and caregivers' views on CHBC Programme	75
4.4	The HIV / AIDS patients and caregivers' views on the state of service delivery and support networks	76
4.5	Inadequate training for the HIV / AIDS caregivers	80
4.6	HIV / AIDS caregiving-a women's role	81
4.7	Social implications of the CHBC for women	82

4.8 Effects of HIV / AIDS care giving on caregivers' health	83
4.9 The caregivers and the HIV / AIDS patients needs	83
4.10 The CHBC team and Policy makers (Councilors) views on HIV / AIDS	86
4.11 The CHBC team and Policy makers' views on CHBC Programme	88
4.12 The CHBC team and Policymakers' views on CHBC Programme Service delivery	88
4.13 The Good hope Chief and headmen's views towards HIV / AIDS	91
4.14 The Chief and headmen's views on CHBC Programme	92
4.15 The Chief and headmen's views on the CHBC Programmes' service delivery	93
4.16 The Spiritual and Traditional healers' views on HIV / AIDS	93
4.17 The Spiritual and traditional healers' views on CHBC Programme	93
4.18 The Spiritual and traditional healers' views on CHBC Programme service delivery	93
4.18 summary	94
5. CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS	
5.1 Introduction	96
5.2 Discussions	96
5.3 Recommendations	101
5.4 Bibliography	102
5.5 Appendix 1	111
5.6 Interview Guide	120

LIST OF ABBREVIATIONS/ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CBO	Community Based Organisations
CHBC	Community Home Based Care
HBC	Home Based Care
HIV	Human Immune deficiency Syndrome
IDU	Injected Drug Use
KABP	Knowledge Attitudes Believes and Practices
KAP	Knowledge Attitudes and Practices
MTP	MID- Term- Plan
NACP	National AIDS Control Programme
NGOS	Non-Governmental Organisations
PHC	Primary Health Care
PLWAS	People Living With AIDS
STD	Sexually Transmitted Diseases
UNDP	United Nations Development Programme
WHO	World Health Organisation

1 CHAPTER ONE

1.1 STATEMENT OF THE PROBLEM.

The overwhelming size of the HIV /AIDS problem in Botswana and the fact that the AIDS Policy and the CHBC Programme is very vital to the socio - economic strategies in Botswana provide the motivation for evaluating the effectiveness of the CHBC programme.

The aim of this study is to establish if the CHBC Policy is achieving its objectives in terms of its intended impact on patients, and if not, to explain what the obstacles are to the effective implementation of the Policy and the programme? It seeks to establish whether the government is fulfilling its part of the CHBC service, and whether communities are adequately well – equipped to fulfill their roles within the CHBC systems?

1.2 HYPOTHESES OF THE STUDY.

The following were hypothesized;

1. The Policy on CHBC is not effective (giving of support spiritually, socially, psychologically, physically and materially), due to shortage of resources.
2. The CHBC programme is not effective as a result of the low support towards it by the communities.
3. The negative understanding of and attitudes to HIV / AIDS by many of the patients and caregivers.

1. 3 DEFINITION OF CONCEPTS

COMMUNITY HOME BASED CARE (CHBC): is care given to individuals in their own natural environment. Which is their home by their families, supported by skilled social welfare officers and communities to meet spiritual, material and psycho - social needs; with the individual playing the major role (NACP 30, 1996: 3)

TERMINALLY ILL PATIENTS: are individuals that have reached their fatal stage of illness.

CARE - GIVERS: A significant family member providing direct care to the HIV / AIDS infected family member (s), such as, spouse, guardian, relative, girlfriend, boyfriend son or daughter.

FAMILY: can be defined differently by different authors. Clemens - Stone, Eigsti and Mcquire (1987) support this view. They state that, varying organisational structures have made the concept of family an elusive one, open to numerous definitions, depending on ones' value system. Hanson and Boyd (1996) state that, " family " is a word that conjures up different individuals.

Families living with HIV/ AIDS: family units that have one or more family member (s) who is/ are infected with HIV/ AIDS.

Family member: an individual who is part of the family unit.

Patient: a family member who is not well and is being cared for.

1.4 SPECIFIC OBJECTIVES OF THE STUDY.

The study seeks to find out the following:

- Whether a CHBC Policy is in existence, and if yes, to identify problems facing it, whether there is enough personnel backup and to gain insight of Policy on CHBC as well as to establish as to whether the Policy is consistent with implementation.
- Whether care - givers are well equipped with guidelines on CHBC.
- Whether there is coordination of activities done to avoid duplication of services or activities.
- What is actually happening on the ground and Whether patients and care - givers are aware of the existence of the CHBC programme.
- Whether patients and care - givers are happy with the provided services
- The support given by the government, parastatal organisation, private entities and the community at large.

1. 5 SIGNIFICANCE OF THE STUDY.

Theoretically the study seeks to provide a comparative perspective to other researchers both locally and abroad. It will provide baseline data on the HIV / AIDS patients and on how best they could be helped. It will provide data which will improve Policy formulation and implementation.

Nationally, the results obtained from the study would be used as a baseline data to other areas of the country. The study will sensitise the Botswana government on how best the terminally ill could be looked after. It is the study's aim to provoke further research in the same area. Internationally the study seeks to provide data upon which other countries might learn from Botswana and give comparative perspective. It will provide strategies and data concerning the CHBC programme.

1. 6 Background information

HIV/AIDS is a global problem for which solutions are yet to be found. By 1996, over 9 million people worldwide had died of AIDS, out of which 7.6 million were in Africa (the Economist, 1996; UNECA, 1996; Hope Sr., 2000).

In Botswana the first AIDS case was reported in 1985. Currently the country is experiencing the severest AIDS infection in the world (NACP 31 2000). In 1992 385 AIDS cases were known, and it was estimated that by 1997, there would be 7,000 cases. In 1992, 60 000 were estimated to be carrying the virus. It was then estimated that the number would more than double to 155,000 by 1992, and 190,000 by 2002 (NACP, 1996).

Botswana occupies the unenviable position of having the highest HIV/AIDS infection rate in the world. Some urban centres such as Francistown recorded the highest rates in Africa (AIDS/STD unit, 1994). This puts the country in a difficult situation as the population of the country was projected to be only 1,66 million in 1997 (CSO. 1995: 3 as quoted by Osei - Hwedie K. and Osei- Hwedie B. 1999)

Mosiilemang, (2001) contends that, it is estimated that 36 per cent of adults in Botswana are HIV positive. This is worse than Zimbabwe at 25 per cent and South Africa at 20 per cent. It is further projected that AIDS will reduce the national budget by 20 percent and reduce the income of the poorest by 13 per cent. Life expectancy is now estimated to be 44 years with AIDS instead of the 69 years it would have been without AIDS.

The rapid increase in the incidence of AIDS and HIV has put the country in a difficult financial position. HIV/ AIDS related cases

dominate the hospital wards and account for 40 percent of the total deaths. Like many African governments, the Botswana government has responded positively to HIV/ AIDS challenge. This is proved by the fact that the Botswana government has formulated a National Policy on prevention of the disease and care for patients. The government has designed and is implementing the CHBC as an instrument for taking care of the infected people. The CHBC Policy adopts the stand that the family and the community are the primary providers of care and support but that, they should be assisted by welfare professionals (NACP,1992).

1.7 THE HIV / AIDS POLICY IN BOTSWANA.

In Botswana, the HIV / AIDS Policy is meant to target the following;

- Socio – economic factors which are attributed to the transmission of the HIV virus.
- HIV / AIDS potential impact on social and economic development. The recognition that only a meaningful national response involving all sectors of society in HIV/AIDS prevention and care will make a positive impact in slowing down the epidemic.

The policy does this by setting out the roles of the following; based on the principle of collective responsibility.

- the national leaders,
- government ministries,
- the private sector,
- non - governmental organisations (NGOS),
- community based organisations (CBOS),
- persons living with HIV / AIDS and
- individual community members (Ministry of Health, 1998)

The Medium Term Plan (MT), 1997 - 2002, on HIV / AIDS , recognises the need for a multi - sectoral and decentralised response to the epidemic. This is based on three main objectives;

- To reduce HIV transmission and to reduce the impact on HIV and AIDS at society's various levels.
- Institutional strengthening and service delivery.
- The Policy's implementation focuses on gender, geographical representation, cultural and religious diversity and key stakeholders. (Republic of Botswana, 1996: 7).

1.7.1 THE OVERALL STRATEGY OF THE HIV / AIDS POLICY.

The Botswana National Policy on HIV /AIDS 's overall strategies are based on the following;

- The prevention of HIV /STD transmission;
- The reduction of the personal and psychosocial impact of HIV AIDS and STDs.
- The mobilization of all sectors, and of communities for HIV /AIDS prevention and care.
- The provision of care for people living with HIV /AIDS and STDs, and reduction of the socio - economic consequences of HIV /AIDS and STDs. (Ministry of Health in Lachman, 1997: 3).
- Since HIV is mainly sexually transmitted, the key element of the strategies for control remains the prevention of sexual transmission.
- Among other things the strategy focuses, on information, education and communication, targeting different groups and using various approaches, promotion and efficient distribution of condoms to appropriate population subgroups, control and appropriate treatment of other STDs, counseling of persons with HIV / AIDS and STDs, and other individuals to adopt safer sexual behaviours and practices.

- Promotion of gender equality in all aspects of national and community life to empower women and improve their socio - economic status.
- The mobilisation of communities for HIV /AIDS prevention and care activities, and encouraging men to use their authority and power in sexual and family relationships responsibly and positively to protect themselves, their partners and family through targeted educational programmes and activities (Ministry of Health, 1998).

1.8 THE COMMUNITY HOME BASED CARE (CHBC) PROGRAMME.

"Community Home Based Care is defined as;

.... The care given to individuals in their own natural environment, which is their families; supported by skilled social welfare officers and communities to meet spiritual, material and psycho - social needs; with the individual playing a crucial role" (Republic of Botswana, 1996a: 3).

The Community - Home Based Care programme resulted partly from the high infection rate of HIV and its impact on health facilities. For example, in 1998, the percentage of bed occupancy rate for HIV related illness in medical and pediatric wards in the two referral hospitals, Nyangabwe in Francistown and Princess Marina in Gaborone were 70 percent and 50 percent, respectively. In the primary and District hospitals, the occupancy of HIV related illness was about 30 percent of the total beds. In spite of these very high figures, upward trends are anticipated (NACP 30, 1996).

The CHBC programme utilises the established, extensive network of hospitals, clinics, and health posts, staffed by professional health workers and social workers. Local NGOs and other groups on prevention and care issues are also brought on board. The target for

the programme is any person with HIV / AIDS related diseases. The professional welfare officers include nurses, social workers, and District Health Education and nutrition officers.

1.8.1 THE RATIONALE OF THE PROGRAMME

The CHBC programme is built on the rationale that;

The home is the best place to care for many of the people with terminal illness. This is based on the belief that traditionally, the extended family is the main source of care and support and resource for people in need of care due to illness. Therefore, the family is always available and well able to share responsibilities for care giving with social welfare workers.

Thus, the programme places the main responsibility for care on the family with social workers and volunteers playing supportive and facilitating roles.

Available information point out to the fact that majority of people with AIDS prefer to die at home among familiar people than in a health facility. To add on this, the rate of infection and hospital admissions indicate that it is impossible to manage the expected number of patients at any quality level. Thus, health care resources are just inadequate for current needs.

The serious inadequacy of health care facilities and workers coupled with the fact that the AIDS epidemic is not sparing even the health workers makes the CHBC programme a very attractive mechanism to the government for looking after people infected with AIDS.

The CHBC programme focuses on the overall goals of the Botswana National AIDS Control Programme to prevent HIV transmission and

reduce the impact of HIV infection and AIDS on the infected and affected. This is shown by the Programmes' objectives.

1.8.2 THE COMMUNITY HOME BASED CARE PROGRAMMES' OBJECTIVES.

The CHBC programmes' objectives are:

- To ensure optimum level of care for all terminally ill patients in order to avoid the " dumping syndrome."
- To avoid unnecessary hospital admission.
- To provide clinical care in the home including giving medications.
- To provide nursing care in a home setting.
- To provide an ongoing counseling service to both people living with AIDS and their families.
- To refer terminally ill patients to social welfare and other appropriate agencies for material support.
- To establish functional referral system between hospitals, district health teams, clinics, and between districts "(Republic of Botswana, 1996: 5).

1.8.3 MERITS OF THE PROGRAMME.

In light of the above objectives the government faces a serious shortage of resources especially manpower, it is believed that the limited health resources could be best utilised by involving and utilising families, social welfare workers and volunteers to care for AIDS patients, and therefore reduce the work load of health professionals in hospitals.

The process as well requires improvements in the system of hospital admissions and discharge to reduce overcrowding and ensure availability of beds when needed.

The family and community members and volunteer's skills will be enhanced in the provision of CHBC. This means that the existing social networks at both the household and community levels will be strengthened and be utilised (Osei-Hwedie,1994).The programme is based on the principle of Shared Rights and Shared Responsibilities, which is the global objective of the World Health Organisation (WHO) on health. This is shown by the fact that, the CHBC concept is based on the " sharing of care tasks between hospitals, district health services, families and the community." Support for families and their involvement in caring for people with chronic illness and during the terminal stages of AIDS is seen as an alternative to prolonged hospitalisation (Republic of Botswana, 1996a: 4)

1. 9 THE SUMMARY OF THE CHBC PROGRAMME

The basis of the CHBC programme, therefore, is the provision of quality care through activities that meet physical, psychosocial and spiritual needs of HIV /AIDS patients and their families.

In light of this, efforts are geared towards assessing the health and health - related needs of patients and their families, developing a plan of action to satisfy the identified needs, providing continuous support and care for the patient family and to identify community support groups, providing training and education for social welfare officers, patients, care - givers and community groups involved in providing care at the home, establishing a comprehensive referral system to ensure continuity of care and monitoring and evaluation of CHBC programme (Republic of Botswana,1996a : 6)

1.10 STRUCTURE OF THE THESIS

Chapter one presents the study, this has been done by discussing the Botswana HIV/AIDS policy, the Botswana policy on Community -Home-Based-Care, statement of the problem, hypothesis of the study, specific objectives of the study, significance of the study and the definition of concepts.

Chapter two discusses literature review, arranged as follows;

- International perspective on the spread of the HIV/AIDS.
- African perspective on the spread of the HIV / AIDS,
- The Botswana perspective on the spread of the HIV/AIDS,
- The GoodHope {study area} perspective on the spread of the HIV/AIDS,
- The theoretical framework guiding the study,
- overview of the Community-Home-Based-Care,
- An International perspective on Community-Home-Based-Care,
- An African perspective on Community-Home-Based-Care,
- The Botswana perspective on Community – Home Based Care,
- The GoodHope {study area} perspective on Community-Home-Based-Care.

Chapter three presents the methodology of the study, The choice of the research paradigm is discussed, the study population, the sampling procedures and the sampling size, the study setting follows, data collection techniques are discussed followed by the study limitations and the ethical considerations.

Chapter four presents data analysis, arranged in the following pattern; Caregivers and the HIV/AIDS patients' views towards HIV AIDS; Community-Home Based-Care, the state of service delivery and support networks; HIV/ / AIDS patients care giving: a women's role, the policy makers and CHBC team views towards HIV / AIDS and CHBC

programme, their views on CHBC service provision are discussed and lastly the views of village leaders who are chiefs and church pastors towards HIV AIDS, CHBC and CHBC service provision.

The last chapter, which is **chapter five**, presents discussions, suggestions and recommendations of the study as well as summary and conclusion.

CHAPTER SUMMARY

This thesis seeks to find whether there is a Policy on CHBC Programme in Botswana, and if yes, the thesis wants to establish whether it is implemented effectively. If not, to identify the main obstacles that, negatively impact on the effective implementation of the programme. The thesis, as well, aims at testing some of the hypothesis and finding out about the objectives that were earlier on mentioned.

It is the aim of the thesis to give a comparative perspective to both local and abroad researchers and to provide data to the Botswana government on how best the CHBC Programme could be implemented. The paper further discussed background information on HIV / AIDS and the HIV Policy in Botswana. The rationale for the CHBC Programme, objectives and merits are presented and lastly the structure of the thesis followed.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents a review of literature on the current trends in the spread of the HIV / AIDS and the performance of the CHBC programme which is meant to care for the HIV / AIDS patients. The chapter starts with the global perspective on HIV / AIDS. This is followed by an overview of HIV / AIDS at the African, national (Botswana) and lastly the GoodHope (study area) respectively. The chapter also gives an overview of CHBC programme and thereafter looks at Botswana perspectives on the topic. The theoretical framework guiding the study is also examined.

2.2 AN INTERNATIONAL PERSPECTIVE ON HIV/AIDS

The Panos Institute, London: 10 July (1996) contends that, "Almost one and a half million people worldwide develop AIDS each year, a figure which will rise rapidly in the next decade. In those countries most heavily affected, the costs of providing care to people with AIDS threatens to overwhelm their health systems"

The HIV/AIDS epidemic continues to spread inspite of joint efforts by governments, non-governmental organisations and societies to bring it to a halt. An increase in the number of heterosexual AIDS transmission in developed countries -- which initially had a higher incidence of infection through injected drug use (IDU) was reported by the World Health Organisation (WHO) in 1997. The developing countries have predominantly experienced and is still experiencing heterosexual AIDS transmission. An increase of 18% in the number of AIDS cases was

reported across the world between 30th June 1996 and 30th June 1997 (Lachman, 1997:21).

It is globally reported that, there is an increase in the numbers of young people infected with the virus. The AIDS epidemic has been described as an epidemic of young people, with 50 % of the new infections occurring to people under the age of 25 (Lachman, 1997: 22). This means that, the economically active youths (workforce) will be killed by AIDS. Hence the economic decline of most countries in the future. South Africa's ex- president Nelson Mandela is quoted as saying that; "AIDS kills those on whom society relies to grow crops, work mines and factories, run the schools and hospitals, thus increasing the numbers of dependents. It creates new pockets of poverty when children leave schools earlier to support remaining children" (Mail and Guardian, Sept. 1997).

2.3 THE AFRICAN PERSPECTIVE ON HIV/AIDS

" Despite all global, regional and individual efforts, the epidemics of HIV / AIDS are growing in developing countries and more especially in the Sub-Saharan Africa, and South-East Asia, although some rates of infection are starting to decline, in specific groups in some countries. In many African countries HIV/AIDS has become a major public health problem of almost unmanageable proportions. It is now widely acknowledged as constituting a significant component of Africa's socio economic crisis (Souleyman, 2000: 6)

Grassly and Garnet (2000: 11-12) contends that, the African region, which has suffered the greatest losses to AIDS, is the Sub-Saharan Africa as it accounts for 84% of all AIDS deaths. This major impact of the AIDS epidemic has lead to decline in economic growth and

development. This is the case because the AIDS epidemic is highly prevalent amongst the economically active population (workforce)

Nathanson, (2000:10) states that, AIDS is killing ten times as many people as war in Africa, of which the majority is in the 15-49 age group. This has led to the following negative consequences;

- economic development is declining
- massive social breakdown
- large numbers of orphans
- The lowering of life expectancy, which results affecting all business, leading to low productivity and profitability.

2.3.1 FACTORS INFLUENCING THE IMPACT OF THE AIDS EPIDEMIC IN AFRICA.

Hope Sr. (1999) asserts that, the World Health Organisation (WHO) and other researchers have identified the major trends within the African AIDS epidemic. It is concentrated primarily in the eastern, central and southern Africa and is largely transmitted through heterosexual and perinatal transmission.

Hope Sr.(1999) sees the following as contributory factors to the spread of the epidemic; -

i. THE ECONOMIC FACTORS

Poverty and economic distress experienced by the citizens of most African countries have contributed to rapid spread of the epidemic. This is the case since Africa remains one of the poorest continents of the world. Low education levels, crowded and unsanitary living conditions, malnutrition, and limited access to basic services, high unemployment rates and rapid urbanisation, all these are highly associated with HIV/AIDS.

ii. THE INFRASTRUCTURAL FACTORS

Most African countries have poor infrastructure as a result of financial distress. For example, in 1985-1995, it was indicated that, the Sub-Saharan population with access to health services stood at 57% compared to 80% for all developing countries; that the population per doctor was 18,488 compared to 5,767 for all developing countries and that public expenditure on health was 2,4% of GDP compared to 2.0% in all developing countries. (UNDP, 1996: in Hope sr.:1999:5).

The Sub-Saharan Africa countries have the lowest ratio of hospital beds to population. There are eight to ten times fewer hospital beds than the average for Europe. (Cabral, 1993).

- Education and information communication are as well a problem in the sense that, in most African countries more people are illiterate and as a result, they cannot read for themselves to understand HIV/AIDS information, especially in rural areas.

iii. THE SOCIO-CULTURAL FACTORS

Some traditions and practices found in Africa tend to promote the spread of the disease. Hope Sr. (1999) contends that, sex outside marriage is usual for women in many of the African countries. He further pointed out that polygamy is a common practice in Sub-Saharan Africa, and this according to (Caldwell et al: 1993) has a serious implication for the spread of the HIV/AIDS epidemic since 30 % to 50% of married women find themselves in this kind of marriage.

Another practice, which speeds up the transmission of the HIV/AIDS epidemic, is the wife inheritance that is practiced in some of the African countries. The tradition demands that a widowed woman must be inherited either by a younger brother -in-law or by an older stepson. This is done to

safeguard the deceased's property as well as ensure that the deceased's children have their mother around to care for them.

Sexual cleansing is another practice, which requires the surviving spouse to have sexual intercourse with a chosen member of the deceased family. This is regarded as an effective way of freeing the surviving spouse from the ghost of the deceased.

Recent research suggests that, there is a direct link between circumcision and incidence of the disease. Lack of circumcision predisposes men to sexually transmitted diseases and possibly now directly to AIDS (Caldwell, 1999). It is contended that many of the African males are uncircumcised and as a result, they are more exposed to the HIV/AIDS epidemic (Merton's and Carael, 1995 in Hope Sr. 1999).

2.3.2 COSTS OF THE HIV / AIDS IN AFRICA.

I. THE SOCIO- ECONOMIC COSTS

The World Bank (1993) has made an observation that, AIDS deserves special attention, since failure to control the epidemic now will result in far more damaging and costly outcomes in the future. Considering the fact that, the AIDS epidemic is not only a health problem, but also far-reaching economic, social, psychological, emotional, physical, and spiritual problems.

II. THE HUMAN COSTS

The HIV /AIDS epidemic will impact negatively on population size and growth rates; WHO (1991) made an estimation that, AIDS will slow Africa's overall population growth rate of 3% by 0,5 %, leading to an average annual growth rate of 2,5 %.

The Panos Institute (1992) has it that, life expectancy in Sub-Saharan Africa end of this century could fall to forty - seven years instead of the average of sixty - two years in the absence of HIV / AIDS.

AIDS has the negative impact on child survival in Africa. Stover, (1994) states that, for east African country, AIDS will increase infant mortality rate by 14 % and the child mortality rate by 20 %.

III. THE SOCIAL COSTS

The HIV /AIDS epidemic will make an estimated number of 10 million children orphans by the end of the century. The deaths will result in a deprivation of skills needed for development, since Africa is still an underdeveloped continent (Storck and Brown, 1992 in Hope Sr. 1999)

The HIV AIDS epidemic has brought about a breakdown of the extended family system because the system is stretched to the limits by the burden brought by the AIDS related caregiving. (Hunter 1990, Kelso, 1994 in Hope Sr. 1999: 69).

IV. THE ECONOMIC COSTS

Panos Institute, 1992; Brown, 1996 state that, the economic costs of the AIDS epidemic can be estimated as the direct costs of medical care and the indirect costs of labour. Representing the loss of income and decreased productivity and output due to long days of illness, deaths, and absenteeism from work in order to care for the loved ones. The HIV /AIDS epidemic poses serious threats to the already fragile economies of the African countries.

The UNDP; (1993) places a cumulative direct and indirect costs of AIDS in developing countries at an estimation of U.S. \$ 30 billion for the past decade

The World Bank (1993) states that, in 1992 developing countries spent about U.S.\$ 340 million to care for AIDS patients compared to U.S. \$ 4,7 billion spent by industrial countries to care for their HIV /AIDS patients.

AIDS patients require long hospital stays, expensive drugs and skilled personnel. For example, the direct costs of HIV /AIDS for South Africa is estimated to increase 79 fold during 1991 - 2000, reaching 19 to 40 % of the total health expenditure (Broomberger et al, 1993, in Woodside et al, 1998:3).

In South Africa the epidemic is projected to reduce the economic growth rate by 0,3 - 0, 4 % annually, which will result by 2010 in a gross domestic product (GDP) 17% lower than it would have been without AIDS and wiping US \$22 billion of the country's economy. (UNDP, 2000:3).

In Botswana the country with the highest per capita GDP in Africa, it is estimated that in 10 years to come AIDS will slice 20% off the government budget, erode development gains and reduce the income of the poorest households by 13 % (UNAIDS, 2000: 3)

V. THE INDIRECT ECONOMIC COSTS

The HIV / AIDS strike the most productive age group in society, and as a result in most societies productivity will be negatively impact on, as well as income and the overall economic development.

At family level, death or illness of main breadwinners is likely to result in absolute poverty family level.

At national economy level, economic productivity will decline as a result of loss of labor inputs emanating from illness, early retirement and death of highly skilled workers.

The AIDS epidemic as well has a negative impact on employment such as training, sickness and death benefits, pensions and insurance (Armstrong, 1991; Ndongko, 1996) in Hope sr. 1999.

There will be need to replace skilled workers; a process that is going to be very costly.

For example, in Tanzania projections indicate that, the cost of replacing teachers lost to AIDS through the year 2010 will be US \$40 million (World Bank, 1993). This is a problem faced by many African countries, and if countries fail to replace skilled labour then there will be shortage of skilled labour. This will in turn impact negatively on productivity and projected economic growth of those countries (Whiteside, 1993:6, Loewenson and Kerkhoven, 1996).

2.4 THE UNITED NATIONS RESPONSE TO THE HIV / AIDS EPIDEMIC.

Since 1986, the World Health Organisation (WHO) has been taking a leading responsibility on AIDS matters in the United Nations. Countries were being helped to set up national AIDS programmes. By the mid-1990s, it was clear that AIDS needs a more concerted United Nations effort, considering its devastating impact on all aspects of human lives, social and economic development.

In order to address the HIV /AIDS challenges, the UN took an innovative approach in 1996, and this was done by drawing six organisations together in a joint and cosponsored programmes. These were the UNICEF, UNDP, UNFPA, UNESCO, WHO and the World Bank--together they form the UNAIDS(WHO:1993).

The goals UNAIDS set for this formidable coalition against AIDS were to:-

- catalyse, strengthen and orchestrate the unique expertise resources, and networks of influence that each of these organisations offers.
- Working together through UNAIDS, the cosponsors expand their outreach through strategic alliances with other united nations agencies of national government, corporations media, religious organisations, community- based organisations.

2.4.1 THE UNAIDS MISSION (OPERATIONS).

UNAIDS is the leading advocate for worldwide action against HIV /AIDS hence its global mission is to lead, strengthen and support and expanded response to the epidemic that will;

- prevent the spread of HIV / AIDS
- provide care and support for those infected and affected by the disease
- reduce the vulnerability of individuals and communities to HIV / AIDS
- alleviate the socio-economic and human impact of the epidemic.

2.5 THE BOTSWANA PERSPECTIVE ON HIV / AIDS.

The Botswana National Policy on HIV/AIDS (1998) records show that; the first case of AIDS in Botswana was identified in 1985; and that significant spread of the HIV in the country started in the mid-1980s. A high rate of the disease's incidence (42.9%) was recorded in Francistown in 1997, followed by 38% in Chobe, 34,4%in Serowe/Palapye, 34%l n Gaborone, 33% in Lobatse.And in five years the rate was said to have doubled. The National estimate of persons infected with HIV is about 14% of the population (207,000). Among this, 25% represents the sexually active productive group. These

findings place Botswana among the worst affected countries in the African region. (Hope sr. ,1999)

2.5.1FACTORS CONTRIBUTING TO THE RAPID SPREAD OF THE HIV / AIDS WITHIN THE COUNTRY (BOTSWANA).

The rapid spread of the HIV/AIDS virus in Botswana is associated with several factors and amongst them are the following;

- The high mobility of the population from towns to rural areas and verse versa combined with good communication system.
- The high rate of sexually transmitted diseases in the country increases individuals' chances of being infected during unprotected sexual intercourse with an infected person (Botswana National Policy on AIDS: 1998).
- Sexual behaviour patterns through use of multiple partners and frequent change of partners which is taken as a rapid spread of HIV norm in rural and urban areas is as well responsible for the /AIDS in the country.
- Rapid urbanisation leading to the breakdown of traditional social mechanisms of control for social and sexual behaviour. For example in 1981, the urban population increased from 18% to 46%. In 1996.

2.5.2 REACTIONS OF DIFFERENT GROUPS TOWARDS HIV / AIDS

Molutsi, et al (1999) in Hope sr. (1999) states that, as a result of increased AIDS awareness programme by the government, society has a better knowledge of the disease; that general awareness about AIDS risk activities is as well high and that attitudes toward HIV/AIDS patients are positive. But surprisingly, there are an ever-increasing numbers of infected persons, despite the dramatic increase in condom distribution throughout the country.

According to Molutsi (1999) men have a low risk perception and denial that AIDS continues to be a threat. A study conducted on men's knowledge, attitudes, sexual behaviour discovered that knowledge and general awareness about AIDS risk activities is high. Surprisingly, perception of the personal risk of contracting AIDS was generally low.

The same study revealed that most youths in Botswana begin sexual activity at an early age, (14 years). A baseline study in 1992, which was carried out by the Young Women Council Association (YWCA) and the World Health Organisation (WHO), on knowledge, attitudes and beliefs and practices (KABP) of secondary school students in Gaborone demonstrated this fact (Republic of Botswana, 1994).

Some serosurvey studies done during 1992, 1993, and 1994 on knowledge, attitudes and practices (KAP) regarding sexual behavior of 18 -25 years old persons showed that;

- Young people have difficulties in linking their knowledge with their own sexual behavior and the need to practice safer sex.
- Half of those surveyed; thought that they could do little to protect themselves from getting AIDS. This feeling of helplessness did not increase with knowledge on prevention and risk factors.
- A major problem amongst young women appeared to be sexual violence. This was shown by the fact that a fifth of young women who are sexually active reported to have been physically forced to have intercourse, whilst a similar proportion reported to have been physically forced to do it the first time they had sexual intercourse.
- A negative attitude towards carrying condoms existed which discourages young women from carrying condoms. As nearly 40%

of males strongly agreed that, a girl or woman who carries a condom is usually a prostitute.

- The practice of multiple partners continued.
- Condoms use was high for casual partners than for serious partners.
- The link between STDs and AIDS was not realised by the youths (Republic of Botswana, 1992,1993,1994)

WOMEN

Molutsi, (1999) states that, more females than men are HIV/AIDS infected, as infection is concentrated in the vaginal fluids. This makes it easier for infected men to pass on the disease to women than infected women to men.

Women are socially vulnerable to the HIV/AIDS pandemic since society expects them to be sub-missive to sex.

2.5.3 WORKERS IN HEALTH SETTINGS.

Research that was conducted by Gabalebatse, 1990; Masololo, 1990; Khani, 1993) in Hope sr. (1999) confirms the adequate knowledge of people who work in health settings, and that they have positive attitudes towards AIDS patients. Surprisingly enough, there is no relationship between their knowledge and preventive measures taken by them.

2.6 CONCEPTUAL FRAMEWORK GUIDING THE STUDY.

A blue print for this study is the Community Partnership theory or the Social network approach.

THE COMMUNITY PARTNERSHIP (NETWORK APPROACH)

This approach advocates for the formation of teams and partnership amongst formal and informal care providers, in order to deliver quality services to patients at a local level. Both formal and informal cares are to be integrated at a local level in the form of a partnership. (Osei-Hwedie, 1998)

Stanhope et al, (1996) have observed that, community partnership is important because it enables community members and professionals to be active participants in a collaborative decision-making process, have common interests in successful community health improvement efforts.

Most changes must have the aim of improving community health through active partnership between community members and health professionals (Stanhope and Lancaster, 1996). In such partnership cooperation, co-ordination, and combination are very essential. In this case Home-Based-Care ideas are to be combined and all parties involved in Home-Based-Care should co-ordinate forces to make a strong base. Partnership ensures continuity of care, and equality among HBC participants.

Client involvement and participation in health promotion and health maintenance is one of the primary health care (PHC) principles of the World Health Organisation (WHO,1978). The gap between professionals and clients is bridged and the parties work as partners. Clients are free to communicate their needs to professional counterparts and expect suggestions as to how to meet those needs.

Partnership ensures good working relationship in HBC, since both parties are involved in collective decision-making. (Williams, 1989)

The social network approach has been deemed as very relevant to this study since AIDS patients need an atmosphere, which promote social interaction with other individuals. Patients need to feel people care and love them. Service provision must be decentralised in such a way that it interface with communities' social networks.

The formal service institutions will pursue community social supports in specific areas of needs, such as providing necessary resources and supportive structures to strengthen them, and use them as a backup or support for formal service provision. (Abrams, 1980) contends that, formal and informal care systems are not necessarily reciprocal or functionally reconcilable. These services are to be interwoven for all services to be mutually reinforced and community care enhanced (Cooper, 1981, in Hope Sr.1999: 5).

Formal care is care rendered to patients (clients) by professionals (doctors, nurses, social workers, social welfare officers etc) while informal care is one given to clients by non professionals (family members, friends, relatives, pastors and volunteers).

Sims, R et al, 1982, state that, the social support network model seeks professionals and non professionals to team up in order to deliver quality services to clients. Sims, et al (1992) state that each individual team member will have their own believe systems which will affect delivery of care but team, as a whole, is to agree on the overall aims of care giving in order to achieve a coordinated approach. These overall aims include the following;

- To provide for the whole needs of the patients
- To treat each person as an individual, with respect and acceptance, acknowledging each person's right to privacy and confidentiality.

- To give control over personal life, back to the patient as far as is possible.
- To enhance the quality of life by good care; including aids for daily living, appropriate housing and effective symptom control. Thus enabling the patient to live life as fully as possible until death.
- To facilitate a comfortable and a dignified death.
- To provide support and bereavement follow up to families, partners and friends, recognising all who are of importance to the patient.

2.7 DISTINCTIVE ROLES PLAYED BY VARIOUS SERVICE PROVIDERS TO THE HIV / AIDS PATIENTS.

FORMAL SERVICE PROVIDERS.

- **DOCTORS:** Sims, et al (1992) see the doctors' roles as of symptom control and management of medical problems directly related to AIDS.
- **THE NURSE:** Henderson (1958) quoted in Sims, (1994) contends that, " the unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery
- **THE PATIENT / NURSE RELATIONSHIP.**
*Relationships are to be based on mutual trust. and acceptance and be confident and relaxed.
- The nurse's knowledge and skills should be adequate to the patient needs as this will help to build confidence in the patient.

- The nurse should facilitate the establishment of good relationships between themselves and patients and ensures continuity of care.
- THE THERAPISTS: The physiotherapists play a vital role in maintaining quality of life for as long as possible. I, e in easing distressing muscle aches and pains, and relieving some breathing difficulties as a result of chest infection.
- THE DIETITIAN: dietitians are very crucial in the overall care for the HIV/AIDS patients, because they are there to give dietetic advice.
- THE SOCIAL WORKER: Social Workers are very crucial in the lives of the HIV/AIDS patients in the sense that they provide social needs. Identifying the history of the current situation of the patient. In most cases strong counseling in-put is needed, to the patient as well as to the patients family.

11. INFORMAL SERVICE PROVIDERS TO THE HIV AIDS PATIENTS

THE FAMILY: Families are very important to people with HIV /AIDS This is because the family home can be a shelter, where patients can be assured that they are loved and accepted, and where patients should be so free that they do not hide their feelings. They feel assured of full support. (Dexter et al, 1983)

- The family helps the HIV /AIDS patients to rest by doing household jobs for them.
- The family provides general care for the patient, eg (washes the patients' clothes and bedlinen)

- The family can buy and cook nutritious food for the patient.
- The family gives the patient love, support that is needed by the patient. (Badisang, 1992: 26)

(Frohlich, 2000: 11) asserts that, home care begins with love, courage, patience and commitment. This implies that family members have to carry out some services such as; meeting the patients' basic needs by providing food, shelter, clothing; helping to take care of their clinical problems, and providing spiritual and psychosocial support through counseling for the patients.

➤ **FRIENDS AND NEIGHBOURS:** This group of people helps patients by giving them societal and emotional support, through spending time talking to patients and their families. They could as well assist the family with simple tasks and errands (Frohlich et al, 2000: 3) such as;

- collecting fire wood
- collecting water
- go shopping on the family's behalf
- cooking food for the family
- caring for the children
- helping in the garden
- cleaning the compound
- washing clothes
- relieve the family care giver

2.7.2 THE APPLICABILITY OF THE MODEL TO THE CHBC PROGRAMME.

The social network theory has been chosen as a guide to this study because of its relevance to the CHBC guidelines.

- ◆ Firstly, the model advocates for partnership or teamwork. In the same spirit CHBC programme is served by a team of professionals (doctors, nurses, dietitians, therapists) and non-professionals (family members, friends, relatives, neighbors, pastors). (See figure 1). This is done in order to give quality service to patients, as well as to share rights and responsibilities. (WHO: 2000)
- ◆ The model advocates for a decentralised service provision. Formal service institutions pursue community's social support in specific area of needs. This is done through the provision of necessary resources and supportive structures to strengthen and use them as a back up for formal service provision. The CHBC programme does this by taking patients from hospitals to their communities where formal and informal care is integrated to deliver good service to patients. The non- professionals are given training on how they should deliver services to patients and their families. For example, caregivers are given training on how to care for patients, in feeding, bathing and counseling them. Pastors are trained on how they are to deliver spiritual support.
- ◆ The principles underlying teamwork concept are the foundations of the CHBC operational guidelines in that, team members (professional and non-professionals) are to cooperate in their discharge of services in order to ensure effective and efficient service delivery. This is fulfilled by the fact that, the team holds meetings, workshops, and seminars to evaluate and strengthen

their work. There is continuous feed back amongst the team and this ensures continuous flow of good service delivery.

- ◆ Teaming or partnering according to its principles is there to provide cost effective services. This is shown by the way the government has taken the patients to their communities to be cared for under teamwork. This gives families and communities to have a helping hand in providing potent care, such that they become part and parcel of the whole thing. This as well will prove to communities of the existence of HIV/AIDS. This acts as eye -opener to societies, and serve the purpose educating the people on prevention and care (NACP,1996).

2.8 AN OVERVIEW OF COMMUNITY HOME BASED CARE.

Woodside et al, (1998) contend that, in Britain, social welfare services emerged in response to the increasing number of the poor. This was the direct result of the crumble of the feudal system, which left the tenant farmers landless. They were forced to drift to cities and towns as a result of the fact that the rural areas had no relief sources. Life in cities and towns was difficult for them, as they did not have skills to earn a living wage. The Industrial Revolution of the eighteenth century together with urbanisation left many people with problems that called for help.

Walker (1992) in Challis, (1990) contends that, community care became explicit after the second world war when the Curtis Committee recommended that children should be cared for in primitive homes or small groups. This was latter applied to care of the elderly people and to mental health service. Community cares for older people first

Made an official appearance in the hospital plan (Ministry of Health 1962) Health and welfare report in the early 1960s (Ministry of Health 1962).

Skidmore (1998) further elaborated that, even in ancient civilisations different attempts were made to take care of destitutes, the poor, the sick, the unfortunate and the handicapped. Many of these were dealt with on a family, neighborhood or religious basis.

In ancient China there were refuges for the aged, the sick, free schools for poor children, free eating houses for weary laborers, associations for the distribution of secondhand clothing, and societies for paying expenses of marriage and burial among the poor and destitutes.

In India, after the Buddha period, there was the giving of the beggars. While in Greece institutions for the unfortunate and the sick were in place. Men who were candidates for public office gave gifts and assistance during the time of the great festivals. There were asylums for wounded soldiers and for abandoned children. In Athens a tax was levied and collected to help the destitutes.

In Medieval time, the church in giving relief as well as in helping distressed persons played a significant role. Monks and Monasteries gave services to care for the indigent, the lame, the halt, and many other unfortunate individuals. Monasteries were there to provide food and housing for pilgrims, soldiers, beggars, and medical and hospital facilities for those in need. The Monks and nuns took care of orphaned or deserted children. This serves as a proof that, across centuries a shift from individualism to collectivism in helping the in need. Mutual aid was and is still a common practice especially with an increase in population and there has been need for societal programmes to help the disadvantage

Community-Home-Based-Care has its roots in the late 1800s in the New York City. It began when the New York City mission hired nurses to deliver medical care and religious services, and to impart health and sanitation to the poor (Woodside et al, 1998). Home health care is meant for delivery of services and products that maintain, restore, or promote physical, mental and emotional health provided to clients in their homes. The purpose of health home care is that of preserving the quality of life for the individual at home by reducing the effects of existing disabilities through non-institutional supportive services (Woodside et al 1998: 23) to people with infirmities and to prevent their isolation from society. "

AFRICAN COMMUNITY HOME BASED CARE (CHBC)

2.8.1 ZIMBABWE.

Zimbabwe has got various CHBC programmes under the control of the government or NGOs. All the programmes work towards the same goal of preventing the spread of HIV / AIDS as well as caring for the infected and affected. For purposes of this discussion, the Zimbabwe National Traditional Healers Association (ZINATHA) will be explored as our case study.

As more and more people were contracting the HIV / AIDS virus the ZINATHA felt a need to start a programme with the aim of decreasing the spread of HIV / AIDS and taking care of the infected and affected (Aglietta, 1987).

The ZINATHA represents most of the traditional healers (herbalists, spirit mediums, faith healers and the traditional midwives) practicing in the country. Under the auspices of the National AIDS Control Programme (NACP) the ZINATHA has developed a national HIV / AIDS prevention project using traditional Care Systems to provide

support to those infected by the epidemic. ZINATHA has developed traditional methods aimed at reducing HIV / AIDS transmission, increase awareness of HIV / AIDS for prevention and care of people with AIDS. Their intention is to create a conducive environment for the already infected to live positively with the disease.

Zinatha seeks to engage in diverse counseling methods to support the use of safer sexual practices.

- ◆ It works closely with the public figures (chiefs, counselors, ministers) in trying to engage them to encourage the modification of traditional practices that encourage the spread of HIV / AIDS.
 - ◆ It seeks to disseminate information to the HIV / AIDS patients and their families of the welfare services available, and how they can get them, as well as the criteria used to get them.
 - ◆ It recognises the home as the best place to care for the HIV / AIDS patients. And as a result communities are encouraged to respect the crucial role played by the extended family in meeting material, social and psychological needs of the infected and affected.
 - ◆ It uses various forms of communities to impart information on HIV / AIDS. These include radios, television, lectures, mass media, drama, and dances to carry out IEC activities in urban and rural areas.
 - ◆ It encourages all healers to register so that they could take part in clinical trials carried out by the Ministry of Health to test their traditional medicines in the prevention and treatment of the HIV / AIDS related conditions.
-
- ❖ The activities, which are carried out by ZINATHA, include the following;
 - ❖ helping to bring about behavioral change such as unprotected sex, multi partners, unsafe medical practices, which could lead to HIV infection.

- ❖ It helps to create a supportive environment for those living with HIV infection.
- ❖ It promotes CHBC initiatives whose aim is to reduce medical, economic, and psychosocial burdens of AIDS.
- ❖ It advocates for quality care of the HIV / AIDS patients and their families.
- ❖ It enhances the HIV / AIDS patients' rights.

ZINATHA'S services range from counseling of the HIV / AIDS patients and their families

It helps with social services such as financial, legal and material support as well as medical care (Aglieta,1987)

The second CHBC programme operating in Zimbabwe to be discussed is the Chirumhanzu Home - Based Care Project.

THE CHIRUMHANZU HOME - BASED CARE (ZIMBABWE)

The Chirumhanzu Home - Based Care Project grew out of an initiative by hospital health workers consisting of senior nurses, Dominican sisters, and expatriate doctors in 1994. The programme is located in the Chirumhanzu District, which is a farming area in the Midlands province of Zimbabwe. This area is so hard hit by HIV / AIDS that the St Theresa Hospital, which is the first - level referral centre in the district experienced over half of the 253 in - patient deaths in 1997 as a result of AIDS. The numbers are increasing at an alarming rate.

The initiators of the programme were concerned by overcrowded hospital wards, and they were aware of the wishes of the HIV / AIDS patients to stay at home under the care of their relatives up to the time of their death. The initiators as well had realised that the ever increasing HIV / AIDS cases will be best cared for under the Home-Based Care scheme. Volunteers to take care of the HIV / AIDS patients

were hunted for in the community and churches, and were trained.

The family members giving care to the HIV / the volunteers who in turn are supervised by the project coordinator and the professional nursing staff at the hospital supervise AIDS patients.

During the 1994 - 95 period, UNICEF financed the project through the Zimbabwean government, and since 1996; some donations have been coming in from the Swiss NGO SolidarMed, German parishes and private donors with Dominican Sister's help. Even though the project is organisationally separate from the St Theresa's Hospital, it collaborates fully with it in referrals and has space in the hospital wing that was built by the Dominican Sisters. The project has got a full time nurse who is paid by the hospital, and the project coordinator is given a small honorarium from project funds. A smaller honorarium is given to volunteers who work for the project. The government mostly provides the nursing materials and drugs in this kind of set up.

The project is founded with two main primary goals;

- to meet needs of the HIV - affected people as close to their homes and relatives as possible.
- To provide necessary information, skills, care, materials, and support to every person who is involved or interested. The project is meeting medical, social and emotional needs. It promotes HIV / AIDS awareness and prevention, among the public and target groups such as sex workers, students, and the STD patients.

The project builds on African traditions of family support and mutual obligation. The persons infected and affected by the HIV / AIDS virus is encouraged to take part in all aspects of the programme. This is a way of increasing the profile of persons living with HIV / AIDS in the community and hence the reduction of stigma amongst the infected and affected.

The project's approach includes three main elements, which are;

- Home - Based care for HIV / AIDS patients
- Support groups for HIV - positive people.

These elements are aimed at meeting medical, social, and emotional needs of Persons with HIV / AIDS.

- Awareness and prevention for the general public and target groups

This element seeks to encourage the local society to take greater responsibility in accepting and caring for its HIV - positive members.

Once an individual is diagnosed HIV positive by the St Theresa hospital, the individual is given counseling sessions as well as assessments that include individual's needs and wishes. When the patient is discharged from the hospital, a letter is sent to the patient's nearest clinic confirming that the patient should be given CHBC services. The trained volunteer will then start visiting the patient once a week. The reports written by the volunteer will be used by the health professionals in deciding the kind of services that are needed by the patient. The project 's volunteers visit popular meeting places with the purpose of imparting HIV / AIDS information to the public.

The HIV / AIDS patients are given self -care training in nutrition, hygiene, techniques such as caring for HIV / AIDS - related skin problems and training on "positive living" with the disease - taking on a forward looking, optimistic attitude. In times when the patient is hospitalised, a member of the family is sent for home care training, which includes, self - care patients, nutrition, hygiene, oral rehydration as well as control of simple infections.

The projects' volunteers are mostly the HIV positive people and some relatives to the infected persons. Of current, the project operates with 30 volunteers. There are as well a number of support groups for

PLWAS in the district. The project employs various ways to impart the HIV / AIDS information to the public. This is done through drama groups. The group performs skits to entertain the public at the same time giving information on HIV / AIDS. Of recent, the project has begun to organise public netball and football clubs for the young people of the community (Aglieta, 1997).

2.9 THE TANZANIAN MODEL

The two CHBC programmes to be discussed are the Kilimanjaro Women group in the fight against AIDS (Kiwakkuki), and the Tanzania people in the fight against AIDS (WAMATA). Kiwakkuki is the name for the Kilimanjaro Women Group in the fight Against AIDS. This is a community based non-governmental organisation. The Kiwakkuki was started by a group of women in northern Tanzania in 1990. They were motivated by the need to join the fight against HIV / AIDS because of the rapid increase in HIV / AIDS cases. The founders of the project felt that women are the most vulnerable and infected within the population as a result, a need was felt for them to be mobilised to protect themselves, their children and their whole community. Their aim was to prevent people from being infected with HIV and to care for those already infected and affected.

Even though Kiwakkuki is women's organisation, its target group is the entire population in the area-- all age groups, sexes and religious groups. The main objectives of the project are to; raise awareness and educate the community, especially women and young people about HIV / AIDS.

- To give the HIV / AIDS patients and their families counseling which help to restore dignity, self respect, and purpose to the lives of

individuals and families affected by HIV /AIDS through the formation of a self - help group.

- To promote understanding and developing a sense of responsibility within communities for HIV prevention.
- To identify and meet the physical and psychological needs of the HIV - infected people and their families and coordinate support for those in need.
- To raise the status of women in family and community life so that women can conduct their lives with dignity and without threat to their physical and mental well being.
- To cooperate with other groups and organisations dealing with HIV / AIDS on all issues including sharing of information and resources.

The Kiwakkuki's believe is that, mobilisation of women to carry out community - based activities for HIV / AIDS prevention and care will bring about social change. At village level, many women have been empowered; they are free to talk about AIDS prevention with their husbands and children. The work of the Kiwakkuki staff of voluntary support to PLWAS and the HIV affected people contributes to reduction of stigma and discrimination surrounding the HIV / AIDS epidemic(Aglieta, 1997).

WALLIO KATIKA MAPAMBANO NA AIDS WAMATA (TANZANIA).

The above-mentioned project is another non- - governmental CHBC programme in Tanzania. It is aimed at fighting against HIV / AIDS epidemic. It is based in Dar - Es - Salaam, and operates in three other regions heavily affected by the disease. WAMATA was created in 1989, when a group of people became concerned about the plight of individuals and families facing the stigma of HIV / AIDS infection. The project started informally with visits to AIDS patients in nearby hospitals as well as offering solace to afflicted families. The objectives are

consistent with those of the Tanzania's National AIDS Control Programme (NACP,1996)

- It seeks to prevent HIV transmission
- It ameliorates the social and economic consequences of AIDS.
- it collaborates with National and International organisations
- it promotes condom use
- it promotes community support
- it conducts research on HIV / AIDS related issues
- To serve HIV / AIDS positive individuals and their families, especially those with a low-income background.
- to support community groups in the care of those with AIDS, and
- to assist in the care of orphans(NACP,1996)

WAMATA works with various non-governmental organisations and other institutions, in its day-to -day range of services like the following;

- it identifies HIV - positive individuals, people with AIDS and their families in need of services
- it carries out home visits including conseling and medical care.
- It disseminates information on the prevention of HIV / AIDS
- It promotes condom use through distributing them
- it educates the HIV / AIDS individuals with AIDS of their rights
- it provides necessities to people with AIDS such as medicine, food, clothes and school supplies for their children.
- It helps families and communities to care for HIV / AIDS orphans (NACP,1996).

2.10 THE CASE OF BOTSWANA

As more and more people contracted the HIV AIDS epidemic, the Botswana government responded by operationalising the twin priorities, which are paramount to containing the disease. --These are prevention measures of HIV and care of those already infected. As a result of the ever increasing number of the HIV /AIDS infected people, the government felt a need to set up CHBC structures in order to care for the victims. Botswana is entering the disease stage of the HIV /AIDS epidemic which calls for an urgent need to put up CHBC structures(NACP,1996:30).

The National AIDS Control programme developed the operational guidelines on CHBC for people with AIDS in Botswana in October 1992.

The cumulative number of the HIV infected people by the year 2000 is expected to increase to more than 300,000.

AIDS is continuing to spread at an alarming rate among the heterosexual population leading to AIDS deaths among young adults, infants and small children. And as a result, the health care system is over whelmed by the epidemic because of its rapid increase (NACP: 1)

The Botswana CHBC programme is reinforced and enhanced into an effective CHBC by the following strategies.

- The **referral system** is strengthened and communication between hospitals and clinics is improved. This is done to ensure continuity of care during the discharge of patients.

- **Community mobilisation:** communities are mobilised to give support especially religious groups and churches interested and with experience in home visits and CHBC, equip them with knowledge, attitudes and skills essential in the implementation, monitoring, and evaluation of CHBC activities.
- **Training:** social welfare providers, caregivers, patients, and communities are to be trained in CHBC.
- **Care:** quality care services will be provided to AIDS patients and their families at home and health facilities.
- **Monitoring and evaluation:** a system to be established for monitoring and evaluation of CHBC The district and hospital staff will monitor progress by measuring outcome indicators.
- **Counseling:** pre and post counseling will be continuously given to patients and their families. In order to provide comprehensive counseling services on HIV /AIDS, STDs prevention and care to individuals, families, and the community for promotion and maintenance of effective CHBC programme.
- **IEC:** there will be information, education and communication on CHBC activities.

This will be done to disseminate information on HIV /AIDS. To individuals, families, communities for promotion and maintenance of quality care to HIV /AIDS infected and affected persons.

- **Coordination:** there will be management and coordination of CHBC activities. This is to establish, develop, and maintain a multi sectoral collaboration and coordination towards implementation, monitoring and evaluation of CHBC activities at all levels.

2.10.1 DEFINITION OF COMMUNITY HOME BASED CARE.

The (NACP,1996:3) defines CHBC as the care given to individuals in their own natural environment, which is their home, by their families, supported by skilled social welfare officers and communities to meet spiritual, material, and psycho- social needs, with the individual playing a crucial role. The target group for this programme is any person with HIV related diseases including all other chronically ill patients. Social welfare officers include nurses, social workers, district health educators and nutrition officers and other allied health professionals.

2.10.2 THE RATIONALE OF THE CHBC PROGRAMMES

CHBC has been found to be the best method to care for many people with terminal illness. for the reasons that;

- The extended family has been the traditional caring unit in society. It will in most cases be available and share responsibility for care with professionals
- Patients prefer to die at home; this has been proved by studies of patients with AIDS in Zambia as well as anecdotal evidence from Botswana.
- Inadequacy of institutional health services since projections for future dimensions of the SIDS epidemic in Botswana showed that it is not possible to manage the expected number of patients in the hospitals and maintain quality care to them. There is a shortage of health care workers to meet current needs of the existing health care system. Considering the fact that the HIV / AIDS epidemic

does not spare health workers as they will become sick and die (NACP, 1996).

The limited health care resources can be employed most effectively and efficiently by using techniques such as:

- Engaging a partnership approach (families, family welfare educators, and volunteers in AIDS patient's care) in CHBC. This will reduce the workload of professionals' health providers in hospitals.
- This helps to do away with overcrowding in hospitals
- This enhances skills of health care providers in chronic and palliative treatment modalities.
- This enhances family members skills and support groups in the community in providing CHBC.
- CHBC ensures sharing of the challenge. This extends the 1995 World Health Organisation, World Aids Day theme of shared rights shared responsibilities, CHBC support is taken as a key strategy to sharing care tasks between hospitals, district health services, families and the community.

This serves as a target for AIDS prevention, since caring for AIDS patients is the best way for families and communities to see AIDS as a reality in the community and for their own lives. This will serve as the best guarantee for prevention of ostracism of people with HIV/AIDS. The optimum goals of CHBC programme is to prevent HIV transmission and to reduce the impact associated with HIV infection and AIDS on the infected and affected. The objectives of CHBC Programmes are:

- to provide maximum care to all terminally ill patients in order to avoid the "dumping syndrome."
- to do away with unnecessary hospital admission
To provide clinical care in the home including giving medications
- to provide nursing care in a home setting

- To provide an on going counseling service to the HIV / AIDS patients and their families
- To equip the terminally ill and their families with material, physical, psycho- social and spiritual support.
- To establish a proper referral system between big and small health facilities, i.e., hospitals clinics and communities (NACP,1996).

The government will ensure that all the HIV / AIDS patients and their families are equipped with the basic necessities. According to the NACP,(1996 :15), these are the CHBC package that the HIV / AIDS patients and their caregivers will use at home and these include materials and medication.

2.10.3 THE CHBC PROPOSED TEAM

- Hospital: doctors, nurses, social workers, physiotherapist, dietician
- Council Health Departments: senior district medical officer, matron, nurses, social workers, AIDS coordinator, district health education and nutrition officer.
- Clinic- nurses, family welfare educators, senior district medical officer, social workers and community health nurses.
- Community - families, non-governmental organisations, red cross, young women council association, Botswana family welfare association, community leaders, village health committees, politicians, headmen, general practitioners and volunteers (NACP,1996).

2.10.4 RECOMMENDATIONS ON CHBC

To make CHBC very effective, the NACP: 30 (1996) reflect that some recommendations were made. Such recommendations include the following;

- every hospital is to have adequate social workers
- health professional staff to be increased in every health institution
- every hospital should have a permanent CHBC coordinator
- Pharmacy technicians to be placed in every clinic to take care of supplies.
- Transport to be increased so that regular follow-ups are easily maintained.
- Communication to be improved in every health institution
- All necessary drugs to be made available to all health institutions

2.11.1 THE CASE WITH GOODHOPE CHBC PROGRAMME (THE STUDY AREA)

As more and more people were contracting the HIV / AIDS disease, The GoodHope district like many other towns and villages in Botswana felt a need of responding to the worsening situation by setting up a CHBC programme in the village. This was a felt need as the already available health facilities in the village were overstretched. The GoodHope CHBC programme does not operate differently from the National CHBC (NACP: 30: 1996). The sub - district has got one referral hospital, and many catchment areas, hence the need for a home based care programme to help the ever-congested hospital.

The rationale, specific objectives, goals, CHBC package, medication package are similar to those stipulated in the National CHBC Operational Guidelines.

Volunteers are selected as per the number of patients per village and are expected to produce weekly written reports. The reports are to cover the volunteers work in the village which in most cases has to do with problems shortage of food for patients, patients' hygiene

in general, inadequate training for care givers and informing the health professionals on HIV / AIDS new cases in the village. They as well help with the bathing of patients, feeding and many other duties.

A number of workshops and seminars have been organised for volunteers to sharpen their skills and knowledge on CHBC. Volunteers have got fund raising committees and with the acquired funds patients are bought basic necessities such as vegetables, fruits and meat. Volunteers have got vegetable gardens where vegetables are produced for patients. In some cases volunteers have erected huts for patients in cases where patients did not have one.

Currently the sub - district has a total number of 206 volunteers of which only 72 are given transport allowance of P100, 00 per person.

Volunteers do experience problems in their day-to-day delivery of services. Transport problems and shortage of staff are the most acute ones.

2.11.2 COMMON ELEMENTS WITH CHBC PROGRAMMES

The overall experience of CHBC programmes is that they all have common elements. Some of which are:

- ❖ With the HIV / AIDS epidemic there is need for a continuum of care, because care and support strengthen prevention. Gant and Ostrow (1996: 14) contend that CHBC programmes for PLWAS came up as a response to the over increasing numbers of HIV positive people who demanded continued care in already inadequate health facilities.

- ❖ There is need for community involvement and the formation of partnerships between government and community - based structures. Evian (1993:14) made an observation that teamwork or partnership provides a better approach at dealing with PLWAS, since the team consists of different professionals and non-professionals who will assist in addressing various problems that the PLWAS encounter. Service provision must be decentralised in such a way that it interface with communities and social networks. The formal services institutions will pursue community social supports in specific areas of needs, such as providing necessary resources and supportive structures to strengthen them, and use them as a back up or support for formal service provision. Abrams, (1980:13) contends that formal and informal care systems are not necessarily reciprocal or functionally reconcilable. These services are to be interwoven for all services to be mutually reinforced and community care enhanced (Cooper 1981:8).

- ❖ CHBC programmes are viewed as the most cost- effective way to address the impacts of HIV, as a cheap alternative to hospital care.

- ❖ In most cases programmes are started and run by strong and determined people, who in most cases are highly committed, resourceful and energetic in carrying out CHBC activities. The reviewed literature on CHBC programmes (ZINATHA and Chirumhanzu) in Zimbabwe showed that these programmes were started and run by strong and committed people. People who started and are running ZINATHA are a group of traditional doctors practicing in the country. They are not paid by government but felt a need to come together and fight the HIV / AIDS scourge. The same thing applies to Chirumhanzu Home-Based Care project, which grew up out of initiative by hospital health workers. They are not

paid for running up the project but get their remuneration as professional nurses where they work.

In Tanzania CHBC programmes have been linked to a range of institutions in order to tap resources from various facilities. Projects have established liaisons with the National Aids Control Programme and a variety of supportive relationships with governmental and non-governmental organisations as well as private sector. These institutions are a major source of information, educational material, commodities, expertise and financial support at times. All CHBC programmes have got volunteers who have an invaluable support in carrying out project activities. This shows that, when volunteers are given appropriate training support and supervision they can educate the public on HIV / AIDS related issues as well as caring for the infected even much better.

CHBC programmes provide individuals and groups with counseling sessions which helps to dispel a sense of isolation and frustration often experienced by those affected by AIDS. All the projects operate under constraints in terms of resources, such as finance, shortages of materials and commodities, medicines, educational materials. The CHBC programmes in developing countries face a serious shortage of resources as in most cases they are funded from outside.

2.12 THE NEEDS OF PEOPLE LIVING WITH HIV / AIDS.

*The overall experience of People living with HIV / AIDS (PLWHA) seems to be that of deepening poverty, isolation, shortage of basic needs such as food and shelter. (Daily News, 25/11/99, Lesetedi, 1998:51) states that there is a strong link between HIV / AIDS and poverty coupled with unemployment, illiteracy and poor health standards. These are cited to be contributing to the rapid spread of the

HIV / AIDS. This is the case because in most cases people do not employ sexual protective measures and end up contracting the HIV virus, of whom the majority are women. The Lund Report (1996), Sewpaul and Rollins (1999:18) have observed that HIV/ AIDS disproportionately affects people who live in conditions associated with poverty, of which the majority is in Africa south of the Sahara. CHBC strategies are to be seen targeting the root causes of the problem such as these ones in order to minimise or do away with the rapid spread of HIV / AIDS.

Fidzani and Atta (1996), in Lesetedi (1998:51) state that in most cases majority of the HIV / AIDS patients and their families end up poor because of the fact that at an early stage of the disease patients consult expensive traditional healers. The same study showed that most patients encounter shortage of basic needs such as food and shelter. The study revealed on how the interviewed patients have indicated that they had gone for days living on soft porridge, and in some cases no food at all. Their recommendations are that nutritional considerations should begin when a patient is first diagnosed as HIV positive. (Casey, 1997:8) and weight maintenance should be a critical part of dietary management goals. Casey finds the need to maintain nutritional status and to show or reverse weight loss as very important.

The other problem facing the HIV / AIDS patients revealed by the Fidzani and Atta study was that of shortage of transport to collect patients to hospitals for medical appointments. The other problem identified was lack of professional support especially counseling. This was identified as a problem as counseling helps the HIV / AIDS patients to live positively with the disease. Without counseling patients and their families are vulnerable to stress, rejection and isolation by the communities they stay in. Counseling as well helps patients to open up and disclose their HIV / AIDS status which will lead to them planning

well in advance in securing their children's future while still in good health.

THE HIV / AIDS patients in most cases are rejected and stigmatised by communities. The HIV / AIDS people continue to be rejected and stigmatised in the communities in which they live in. Webb (1997: 7) has made an observation that the pattern of stigmatisation and rejection of PLWAS applies equally well to the HIV/ AIDS people worldwide, where people experience ostracism and rejection because of their HIV /AIDS status. It has been observed that many people are not in a position to disclose their HIV status. This is attributed to fear of stigma and rejection by their communities (Mercury 15/08/1999, Mail and Guardian 1999). This is supplemented by the fact that Gugu Dlamini an AIDS activist got murdered in Durban following her going public about her HIV status. The reviewed literature of Botswana discusses about a "kgotla" meeting that was addressed by Helen Ditsebe an AIDS activist, which ended up with the crowd being angry and commenting that the HIV / AIDS people must be killed to avoid further infection.

The main problem contributing to fear of disclosure of ones status is the fact that there are no support structures, which could protect them from fear and rejection by communities and society at large. Mthembu (1998) in Frohlic (2000:9) holds the view that is necessary to create strong support structures and services before engaging in mass disclosure campaigns. The CHBC Programmes carried out by various countries seem to share common elements of success and challenges.

2.12.1 ADVANTAGES OF CHBC PROGRAMMES.

- ❖ CHBC programmes are very cost effective in service provision. For example, a study in Zambia revealed that, each home visit costed US \$2.00 as compared to an average daily costs in hospital of over US \$4.00 (WHO: 1993)
- ❖ In most cases in developing countries hospitals are congested with the HIV / AIDS related diseases. And are not coping with the ever increasing number of the ever increasing cases of HIV / AIDS cases. As such CHBC programmes are a way of relieving hospitals from being over flowing. "In most countries in East, Central and Southern Africa, over 50% of hospital beds are currently occupied by people with HIV / AIDS. In Zambia, over half of hospital patients with tuberculosis are HIV / AIDS positive."
- ❖ In most cases the HIV/ AIDS patients prefer to be cared for and die at home as against to being at the hospital. As such they derive benefits from being in a familiar and caring environment, they are happier, suffer less from pain and live longer. And this acts as a powerful way to breakdown prejudice and to inform and educate people about HIV / AIDS.
- ❖ The HIV / AIDS patients and their families gain from the services that are provided by the CHBC team of professionals and non- - professionals.
- ❖ CHBC programmes encourage support as well as participation of local leaders in AIDS prevention and care activities. This gives them an assurance that, they are part and parcel of the programme as opposed to the programme having been imposed on them.

- ❖ CHBC programmes are seen to be powerful tools of integrating people with HIV / AIDS in to the community as is one of the most effective forms of confronting discrimination and educating people about HIV / AIDS.

2.12.2 DISADVANTAGES OF CHBC PROGRAMMES.

- CHBC programmes could be an excuse for governments to opt out of caring for people with AIDS altogether.
- There are reports, which indicate that, many people with HIV / AIDS in the community are not looked after and die from neglect or are actively discriminated against.
- In most cases the CHBC programmes are not well coordinated and as a result the HIV / AIDS patients suffer the results.
- There is no assurance on how cost- effective and how sustainable CHBC programmes are. Since most of them are funded by International organisations such as the German government agency, The USA agency and the Catholic non- - governmental organisation. The danger lies in that; with out more support from developing countries governments, these programmes are likely to collapse should International support be with drawn.
- Balinsky (1994) in Hope Sr. (1999:4) in a study which looked at home care, revealed that, CHBC programmes on its own, will increase costs due to the following;
 - there is a need to increase the number of professional staff members to visit patients in their homes, whilst some are expected to remain in hospitals.

_ there will be more need for transport to be able to conduct daily visits to patients.

- Home visiting teams are not cost effective, since costs include transport and allowance.
- Relatives lose time from work while caring for patients in the home. For example, in South Africa it was found that, teams spent over a third of their time in vehicles driving between patients. Another third spent on planning, meetings and administration.
- Most of the HIV / AIDS patients carers are women, as such this places added burden on women, or families and this gives an overwhelming strain on them. Bearing in mind that, women are already over staffed with family chores (childcare, cooking, general cleaning in the home). For example, a study in Uganda revealed that, of the 30 HIV / AIDS patients, one carer was looking after 13. For a man this was his wife, for an ill patient woman usually mothers are carers, and three were cared for by young children.
- In most cases the first person to be come ill in the family is the breadwinner. Consequently, the incomes lost to this person's illness as well as incomes lost to the careers give the family a double financial burden. As families have to care for the patient's children whom will continue even after the patient's death.
- In most cases CHBC programmes have co-ordination and organisation problems, such that some families may end up receiving no help. Whilst some may be assisted by several agencies.

- In most cases there is inadequate information or education for carers of the HIV / AIDS patients, and as such they are vulnerable to contracting the HIV virus. Such as in cases where the patient is having persistent diarrhea there is need for carers to use gloves.
- CHBC programmes can leave the patient vulnerable to discrimination. For example, April Thomson a nurse working with AIDS patients in Jamaica experienced cases where AIDS patients were left out in the rain, left in pig pens and chicken coops. A woman caring for her daughter in Nicaragua states that, " we do not receive any support from the community or from our neighbours. They say bad things about us. They say that we are the family with AIDS. (PANOS: 1996).

2.13 SUMMARY

This chapter reviewed the literature on HIV/AIDS and the CHBC with the sole purpose of learning from the existing body of knowledge in the field of this research project and to be in the position to place the study in the general body of scientific knowledge. The literature on HIV/AIDS was first probed to provide current perspectives at global, continental national and local levels respectively. The review of literature on CHBC thereafter followed suit.

The literature reveals that the CHBC scheme is fast becoming the most feasible and viable option for taking care of the overwhelming numbers of HIV/AIDS patients in the developing countries, particularly Africa. --Given the small capacity of the formal health delivery system. But the scheme has its own problems to contend with.

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

This chapter discusses the research methodology used in this study. Bailey (1987:3) defines methodology as the philosophy of the research process. It entails articulation of assumptions and values that provide the rationale for undertaking the research and the standard that the researcher will use to interpret data. This research is a qualitative exploratory study in which a social network (partnership) theory was engaged for data collection and data analysis. The methods used include open interviews, case studies focus group discussion and participant observation.

3.2 THE QUALITATIVE RESEARCH PARADIGM.

The qualitative research states the dynamic, holistically and individual aspects of the human experiences and attempts to capture those aspects in entirety within the context of those who are experiencing them (Polit and Hungler, 1998: 5). In the same spirit this study seeks to holistically explore the practice of CHBC in the context of the HIV /AIDS pandemic. These methods can be used to uncover and understand what lies behind any

phenomenon about which little is known in the same spirit, this study seeks to provide the opportunity to understand how policy makers, caregivers, the HIV /AIDS patients and the CHBC team perceive CHBC and HIV /AIDS. The major principle driving the qualitative research is the understanding of the contextual meanings and the patterns of relationships in the phenomena being studied. The aim is that of collecting in-depth information from the subjects being studied in order to fully understand the subjective experience of phenomena (Marlow, 1998). To collect rich and in-depth information these methods provide for a small sample.

The qualitative research methodology allows the researcher and the research participants to deeply explore the experiences and knowledge of the research participants. These methods acknowledge the meaning and understanding of social phenomena as being derived from the interaction of people and the social world. This characteristic of qualitative research is very vital to this study as CHBC happens in the interactive relationships. The case of policy makers, CHBC team, the HIV /AIDS patients and caregivers interacting in order to come up with quality services for patients will be an example. Hence the social network (partnership) theory was adopted for this study in order to show how distinctive parties play out their distinctive roles in the provision of services to the HIV /AIDS patients.

This approach has been found to be relevant to this study because physiological and social aspects of CHBC for PLWAS are to be understood from the consumer's perspective. The service provider's view of CHBC needs to be put within context with policy requirements and views of service consumers need to be addressed within policy as well as the study's findings.

This study seeks to satisfy the researcher's curiosity and desire for better understanding of the CHBC programme. Whether CHBC makes its required impact on the HIV /AIDS patients, and if not, to locate hindrances towards effective service provision. To find out whether the government is fulfilling its part of the CHBC network. To find out whether communities are well equipped for the CHBC programme. At the end the study will make recommendations geared towards improvement of the CHBC programme.

3.3 POPULATION OF THE STUDY

The target study population chosen randomly were the policy- makers, CHBC team, the HIV /AIDS patients and the caregivers to the patients. Out of fifteen policy makers ten were interviewed, out of forty CHBC team ten were interviewed and out of twenty patients and caregivers ten from each group were interviewed. To enrich the collected information, five spiritual healers and the same number of traditional healers were interviewed. The same number of village headmen and the village chief were as well interviewed.

The following table shows respondents of the study as well as the number, which was interviewed, from each group.

INTERVIEWS	NUMBER INTERVIEWED
HIV / AIDS PATIENTS	10
CAREGIVERS	10
POLICY - MAKERS	10
SENIOR DISTRICT MEDICAL OFFICER	1
MATRON	1

CHBC COORDINATOR	1
SENIOR NURSING SISTERS	2
SENIOR DISTRICT MEDICAL DOCTOR	1
SENIOR SOCIAL WELFARE EDUCATORS	2
SENIOR SOCIAL WORKERS	2
NGO REPRESENTATIVE	1
SPIRITUAL HEALERS	5
TRADITIONAL HEALERS	5
VILLAGE HEADMEN	5
VILLAGE CHIEF	1

3.4 SAMPLING AND THE SAMPLING SIZE

Sampling involves making decisions about who will be participants of the study. Sampling entails the selection of a subset of some predetermined size from the population being studied where those selected will become participants (respondents) of the study. The sampling basic principle is that, the sample should be representative of the population of study. In qualitative research studies, selection of an adequate and appropriate sample is critical and the quality of the research is contingent upon the appropriateness and adequacy of the sample (Bailey, 1987).

Polit and Hungler, (1995) state that, a major concern in research is the number of participants needed in a sample. In qualitative research study the sample is to be typically small. This is the case because researchers who use these methods are interested in studying intensive phenomenon. Small samples allow researchers to capture quality data (Strauss and

Corbin, 1990). Small samples are time and energy economic (Polit and Hungler, 1995).

3.4.1 SAMPLING AND ACCESSING PARTICIPANTS.

This study used a non- probability sampling method, because of its usage of the qualitative research design. Marlow (1998) contends that, the sample should be information rich.

The non-probability method that was engaged by this study is called the purposive sampling method. Morse (1991) states that, purposive sampling leaves room for the researcher to select participants according to the needs of the study. Purposive sampling was employed for this study as it involves conscious selection of certain subjects by the researcher, (Burns and Grove, (1997). Purposive sampling is the selection of informants best able to meet the information needs of the study and who are willing to share the information with the interviewer. Bless and Smith, (1995) states that purposive sampling is also known as judgmental sampling. I, e the researcher can use her /his own judgement in selecting the samples. In this study, an information rich sample was obtained from policy-makers, who are responsible for policy formulation, the CHBC team and the caregivers to the HIV /AIDS patients who are responsible for the implementation of policies and the HIV /AIDS patients who are the main service consumers.

The research participants were followed to their homes, and interviews were conducted in-doors or out-doors depending on the participant's (caregivers and HIV /AIDS patients) choice. The researcher was introduced by the senior social welfare officer to volunteers who in turn introduced the researcher to the HIV /AIDS patients and their caregivers.

Members of the CHBC team (mostly nurses) and the policy-makers were followed to their offices in order to give them questionnaires. A sample of ten (10) respondents was selected from each group. In order to get information rich data five spiritual healers and the same number of traditional doctors was interviewed. The chief as well as five headmen were also interviewed.

To enhance the value of the collected data, triangulation of methods was used for data collection. Polit and Hungler (1995) state that, triangulation is when more than one data collection methods are used. This study therefore, employed the in-depth interviews, focus group discussion and participant observation.

3.5 THE STUDY SETTING

The study was conducted in GoodHope Sub - district in Botswana. Goodhope is the Barolong sub – district. The village is one of the traditional villages of Botswana and is situated 50kms from the Lobatse town and 150kms from the capital town of Botswana (Gaborone) and 40kms from the South African boarder post (Ramatlabama)

The villages' catchment areas are Phitshane - Molopo, Mokatako, Mokgomme, Mmathethe, Magoriapitse, Motsentshe, Pitsane, Tihareselele, Pitsane - Potlokwe, Bethele, Mabule, Tshidila - Molomo, Mmakgori, Metlobo, Herbron, Selokong, Phifetshwane, Ramatlabama, Rakhuna, Papatlo, Digawana, Gathwane, and Mogojogojo.

There is a high mobility between the village and the nearby towns and catchment areas. Most movements from the village to towns are in search of employment as the village suffers a high unemployment rate (Population and Housing Census 1991: and Ministry of Finance and

Development Planning, 1991 - 2021). The village has got a few government offices, a clinic, a primary school, a community junior secondary school and a police - station.

The residents of Goodhope strongly believe in the use of the three available health care delivery systems in the country, which Kupe (1993) states them as the western, traditional and the spiritual one.

3.6 DATA COLLECTION

This section discusses the data collection instrument or research tool used for collecting data in these studies. In order to collect information rich data, the study employed a small sample size and used structured in- depth interviews; a pilot study was as well carried out to try the viability of the questionnaires.

3.6. 1 PILOT STUDY

Pilot study involves testing the actual programme on a small sample taken from the community for whom the programme is planned. This gives an early signal of whether there are difficulties with the chosen method or materials to investigate the accuracy and appropriateness of any instrument that have been developed.

The interview guide was pilot tested on a convenient proportion of the population. This was carried out to ensure comprehensiveness and clarity of the tool and rigor. The pilot testing was carried out after permission was sought from the District officer, the Council Secretary, the Matron the CHBC Coordinator and the Senior Welfare educator in the Sub-district.

The findings of the pilot study were that, there was a very serious stigma and secrecy attached to the HIV /AIDS pandemic. The feelings were that, the interviewer should avoid the use of the word AIDS when addressing the HIV /AIDS patients. The pilot study revealed a high shortage of resources faced by CHBC programme.

3.6.2 THE INSTRUMENT FOR DATA COLLECTION

This study employed structured in-depth interviews, with the aid of an interview guide. The interview guide was developed to help direct data collection. The guide was divided into two sections. Section A dealt with the interview protocol and section B dealt with the major part of the guide. The guide was prepared in English and was translated into Setswana where necessary. The policy-makers and the CHBC team were given questionnaires to self-administer themselves, since they are literate. While caregivers and patients were involved in direct interviews, since a majority of them are illiterate. Literate patients who were found to be weak to fill in the questionnaires were as well helped in the filling of the questionnaires by the researcher.

Focus group interviews and in-depth interviews were used to collect information from the policy-makers. The focus group discussion refers to a situation where a group of people is brought together to discuss their lives and experiences in a free flowing, open-ended discussion (Grinnell, 1993) Group work helps the researcher to gain access to inter subjective experiences shared by the group (Kelly, 1999). The focus group discussion method was preferred when interviewing policy-makers (counselors) because they were all councilor, doing the same work for the government. This helped the researcher to explore their feelings and experiences and attitudes towards CHBC. During the discussion

participants felt that CHBC programme is a good idea, while the obstacle hindering its effectiveness is shortage of resources.

3.6.3 PARTICIPANT OBSERVATION

This method was as well employed to enable the researcher to verify between the information gathered through participant's responses to in-depth interviews and the information from their observed behaviour and non-verbal cues. (Leininger, 1985 and Wilson, 1985) see participant observation allowing for validation and complementation of the information obtained from the in-depth interviews.

The researcher was working with the CHBC team for a period of a month gaining informal information. During this period the researcher was in a position to attend CHBC meetings as shown by the below table. The researcher was as well in a position to conduct home-visits seeing patients in their homes, which are their natural environments. This gave the researcher a deep insight into the research problem.

The following table shows the CHBC meetings that were attended by the researcher during the fieldwork period.

ATTENDED MEETINGS	DATES
CHBC VOLUNTEERS' MEETING	JULY - 05 - 2000
PASTOR'S FIGHT AGAINST HIV / AIDS	JULY - 10 - 2000
CHBC EXECUTIVE COMMITTEE	JULY - 15 - 2000
KGOTLA HIV / AIDS MEETING	JULY - 20 - 2000
FULL COUNCIL MEETING	JULY - 25 - 2000
SUB - DISTRICT GENERAL MEETING	JULY- 30 - 2000

3.6.4 THE RESEARCHER'S OBSERVATION

Knowing very well that HIV /AIDS is a fatal infection. The researcher did not think that the situation out in the field was so bad and disheartening. The situation is so sensitive. In most cases patients did not have enough bedding, pillows to prop the patient up, mattresses to give the patient a cushioning, as most of them are bony and skeletal resulted with patients lying flat on an un-cushioned ground.

In some families patients and caregivers will tell you that they have gone for days living on soft porridge, as there is no food. And this appeared strange to me because the HIV /AIDS patients are high in need of food especially protective food to boost their immune system fight against diseases, body building food to repair worn out tissues as well as energy giving food to keep them strong.

In most cases HIV /AIDS patients struggle for oxygen and this state alone is so pathetic to an extent that some family members end up crying seeing as to how the patient is fighting to get air. It was very sad and frustrating to find out the difficulties and agonies that families living with AIDS were going through.

In most cases there is denial of the diagnosis of AIDS by patients and caregivers. This lead to most of caregivers declining from taking precautions to protect themselves from the HIV infection. They were not putting on gloves. The other very pathetic issue is the one in which patients and some family members were seen sharing the same room for accommodation. As this is a health hazard since HIV is infectious, and the rooms were found to be congested.

3.7 DATA ANALYSIS

Data analysis began with reading of field notes, and were checked for quality to ensure completeness, and were properly written and coded with subsequent interviews, continuous observations in the consistency of emerging patterns and themes was made. Marlow (1998: 211) see the primacy mission in analysis of qualitative data as being of looking for patterns in the data, noting similarities and differences. After making patterns and themes, these were pulled to form categories of an identified phenomenon.



3.8 ETHICAL CONSIDERATIONS

This study has been a very sensitive one by its nature. HIV \ AIDS is still taken as confidential and its sufferers under no circumstances allow to be labeled as HIV /AIDS patients. Because of the nature of the study, all participants in this study were assured of absolute anonymity. This is why the questionnaires for this study did not have portions where the HIV /AIDS patients respondents were to fill -in their names. Respondents in this study were assured of absolute confidentiality. They were assured that, data will only be used for the stated purposes of the research and that no other person will have access to interview data. This was done to make respondents feel free to give honest and complete information.

The research participants were informed about the purpose of this study and were notified of their right to decline participation if they so wished. Grinnel (1993) states that, research participants must be competent to give consent and this requires that, they must be provided with sufficient information to enable them to make informed consent. The HIV /AIDS

respondents were consulted and were informed that, those who do not feel to make contributions to the study were free to decline. At the same time, they were notified of the fact that, the study was meant to inform policy-makers to improve conditions in CHBC. That is to say the study is meant to help them.

3.8.1 POTENTIAL PSYCHOSOCIAL CONSEQUENCES OF RESEARCH INTERVIEW

HIV / AIDS is a very sensitive area of study, especially when discussing realities of fully blown AIDS with the HIV /AIDS patients. This discussion with the already infected respondents have the potential of evoking the painful realities about the extent of pain and helplessness PLWAS get into when they become terminally ill. Under these circumstances the interviews took the form of case study therapeutic sessions to enable them to reflect on the realities of terminal illness.

3.9 DISSEMINATION OF RESEARCH FINDINGS

The findings of this study will be availed to the public and research participants. It will be made available to relevant authorities of areas where information was collected. The researcher will see to it that a report is written on the study findings and will be submitted to the relevant authorities. The researcher will see to it that a feedback of the findings is given to the relevant authorities in one of the sub - district meetings. Copies will be made available in the University library and publications will be made in newspapers.

3.10 LIMITATIONS OF THE STUDY

SAMPLING: The sampling method (purposive or judgmental) employed in this study has a limitation in that, a small sample size was engaged, and as a result it cannot be concluded that, it is representative. This sampling technique used in this study has got limitation in that the researcher was the one who handpicked the research participants. This alone makes the samples representative of the larger population questionable. Even though the study used a small sample size, it is according to the qualitative research rules to use a small sample size in order to collect information rich data. As a result this study has collected quality rather than quantity data, as the study has benefited from the in-depth information obtained from the small sample that was used.

THE FOCUS GROUP DISCUSSION: This research method, which was used in data collection, has got some limitations as well. This is because some group members were more dominant than others and as a result data was not collected from all the members. Even though all the group members were encouraged to share their feelings about the topic of discussion.

REFLEXIVITY: It refers to constant reflects on oneself to ensure that there are no biases to the study due to one's beliefs and experiences. Morse (1991) sees, reflexivity conceptualising of what goes on in a researcher during the research process. Miles and Huberman, (1994) made an observation that, in qualitative studies, reflexivity is employed to strive for objectivity and exclude biases. Reflexivity is incorporated in to the research method to offset researcher bias. The researcher as a data-collecting instrument should be reliable in measuring accurately (Wilson, 1985).

the results mean? Unless we can be sure that our techniques are actually measuring the things that they are supposed to be measuring, we cannot be certain what the results mean (Bless and Smith 1995).

The validity of qualitative research can be verified by taking the research findings to research subjects. This as well helps to minimise the extent to which personal preconceptions can influence the study ' s findings (Silverman, 1994)

]

SUMMARY

This chapter discussed the research methodology used in this study, the research paradigm, and the rationale for selecting it as well as its strengths and weaknesses. The chapter that follows discusses the analysis of data.

CHAPTER FOUR

4 DATA ANALYSIS

4.1 INTRODUCTION

The Community Home Based Care programme in Botswana operates within the framework of the operational guidelines for CHBC (NACP, 1996:30) for people living with AIDS. The Operational Guidelines for CHBC programme for people living with HIV / AIDS in Botswana has comprehensive guidelines that define CHBC and outline its goals and objectives as stated in the introductory chapter of this document. The Operational Guidelines as well describe the National strategy for an integrated model of the CHBC programme.

This chapter presents an analysis of the data collected during the fieldwork aspect of the study. The respondents of this study were the following; the HIV / AIDS patients – 10, Caregivers to the HIV / AIDS patients – 10, various health professionals – 10, Policy makers – 10 and the Goodhope village authorities - 17. This study was conducted during the July month in 2000.

The data is a reflection of the opinions of the research participants on the following key issues ---attitudes towards HIV / AIDS and CHBC programme, their needs, and effectiveness of service delivery--which formed the focus of this study.

4.2 THE HIV / AIDS PATIENTS AND CAREGIVERS VIEWS TOWARDS HIV / AIDS.

50 % of the HIV / AIDS patients and caregivers were of the opinion that, HIV is not a viral infection. Instead they attributed the disease to witch craft. They have the believe that the HIV / AIDS patients have been bewitched by their closest relatives who want to get rid of them. Majority of the respondents in this group had never been to school and only a few of them went as far as standard seven (primary educations). This makes the researcher to conclude that, people of low education background holds this kind of believe about HIV / AIDS transmission.

The remaining 50 % of the research participants' opinions were that HIV / AIDS is a result of a viral infection. These participants very well understand the modes of transmission of the disease. Most of the respondents from this category have good education background (secondary and tertiary education), and hence a better understanding of the modes of transmission of the HIV / AIDS virus.

The findings of this study confirm that, fear of disclosure of persons' HIV status is a major problem. The study revealed the reluctance to disclose ones' HIV status as being a result of stigma, rejection and discrimination that PLWAS are subjected to in society. (The Mercury, 1999:8, Jackson 1998, Sewpaul and Mahlalela 1998) contend that, the reaction of the non - stigmatised towards the stigmatised are essentially negative.

" By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination. Through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his / her inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class...further we may perceive his defensive response to his situation as a direct expression of his defect, and then see both defect and response as just retribution for something her or his parents or tribe did, and hence a justification of the way we treat him." (The Mercury, 1999:8, Jackson 1998, Sewpaul and Mahlalela 1998).

The research participants interviewees, caregivers and the HIV / AIDS patients disclosed that, in most cases PLWAS do not say they have got AIDS because of the fear that people will not speak to them and they will be discriminated against and rejected. In most cases PLWAS prefer to deny their HIV positive status. A situation, which is dangerous to care givers, in that instead of them adopting precautionary measures when handling PLWAS, they do not. As a result caregivers end up being infected with the disease and in some cases dying before their patients.

One caregiver commented on non-disclosure and said; " In most cases the health professionals do not tell us about our patients' HIV status. And our patients will keep on telling us that they are TB sufferers, and some patients only tell us about their HIV status when they are dying." Webb (1997: 174) believes that, leading public figures " must come out " with their HIV status for people to understand that HIV is not a disease restricted to prostitution, as most people believe. By doing so, stigma will be reduced on PLWAS.

The research participants (caregivers 90%) showed a concern that, the issue of confidentiality of their patients' illness is very risky to them. They pointed out that caregivers to PLWAS must be given full knowledge of the HIV / AIDS status of patients for them to exercise protective measures in their day-to-day delivery of services to patients.

The problem lies in the fact that, ethically confidentiality requires that professionals are not to disclose the HIV status of their clients to other people without clients' consent. This is even dangerous to one's spouse since if the HIV positive spouse does not give consents that his / her partner should be informed of his / her HIV status, the other partner stands a good chance of being infected as well. PLWAS who refuses to disclose their HIV status are regarded as exercising their right to self - determination. A professional working with PLWAS is only free to disclose his / her status to the PLWAS sexual partner, if it is believed that the partner is at a risk of contaminating the disease. (HIV / AIDS and the LAW, 1997: 54) This is an indication that, PLWAS have rights to self - determination for as long as they do not endanger those who are living or closest to them. To this effect, there is great need for conducive environments to be created to help PLWAS to disclose their HIV status without fear.

Most caregivers (90 %) and some few patients (20 %) believe that, the fear to disclose ones HIV status results in misleading the whole family. This is the case because in most cases if a family member is not well, he / she is firstly taken to consult expensive traditional or spiritual healers. It is only when the family is bankrupt that it will resort to

clinics and hospitals. This is a drawback in that; the money, which could have been used to cater for the patients' basic necessities, is "thrown away". This is the very thing that results in many HIV / AIDS patients dying leaving debts and children starving behind. This sounds more confusing because even for the HIV / AIDS patients who have good education and know very well the modes of transmission of the disease prefer to be treated by traditional doctors and spiritual healers before visiting hospitals and clinics.

"This issue of going public about ones HIV / AIDS status is very worrying, because of the mixed response people who did have received from society." So we find it difficult to go public about our HIV status. For reasons that one has enough problems of being HIV positive and yet ones family could have a negative feeling towards the person once it is known about ones HIV status. We do not know what to do my friend, we prefer death to being looked and pointed at by people making village talks out of us."

These words from an HIV / AIDS positive research respondent shows how it is difficult for him to disclose his HIV positive status. This statement is supported fully by what an HIV / AIDS person who has gone public about her HIV status once experienced when addressing a "kgotla" meeting in the Maun village. This is what she said;

" People with HIV have been demonised and dehumanised. After my "kgotla" meeting presentation on HIV / AIDS, one of the question that was posed was that, why the Botswana government not respond to AIDS infected individuals by quickly killing them to prevent further infections like it was the case with foot and mouth disease?

This shows that there is still a strong stigma attached to the HIV infected people and as a result they find it difficult and hurting to disclose their HIV positive status when there is no societal support for them, and are not respected. This proves that there is still the need for society education on HIV / AIDS related matters because unless and until society has a positive look on the already infected, AIDS will continue to spread. There is a need to educate society on the HIV / AIDS transmission modes in order to stop

them from attributing HIV / AIDS transmission to witchcraft.

4.3 HIV / AIDS PATIENTS AND CAREGIVERS' VIEWS TOWARDS CHBC PROGRAMME.

The research participants (100%) prefer home-based care to institutional care. The patients felt that, it was good for them to stay with their children and have their last words with them before they (patients) die. One of the patients mentioned that, " I prefer home based care because even if I am in the terminal stage of the disease, I will not be chased away like hospitals do. "

This finding absolutely confirms assertions by Zippel, S. et al in Jager, H. (1998) who give a host of reasons why this is so.

*Home based care is preferred to hospital care because patients and relatives have an opportunity of experiencing the last days of the dying persons' life in a community and of doing so without restrictions imposed by strangers (hospital workers).

- Relatives and patients have more control over their situation. The feeling of hope and hopelessness often diminishes; relatives are therefore less often left with the feeling that they personally could have done better.
- Radical life (or better still, death) prolonging measures are not easily achievable at home and are therefore seldom used when acute crises occur. Nevertheless they remain available in emergencies.
- The intimacy of the household atmosphere facilitates psychological well being which is shown most clearly in the reduced employment of pain-killing drugs. The dying person has more opportunities to influence his own quality of life and can feel more accepted in his dying
- Patients have the assurance of finding a caring person to talk to at any time of day and

night. This is vital to the dying and relatives.

- It is more acceptable to die at home in the place where a few decades ago the great majority of people passed the last days of life.

The research participants (patients) gave the following reasons for their preference of CHBC over hospital care.

*Home is an environment they are used to, and as such they feel free and comfortable.

- They feel welcome when their families show a sense of love, acceptance and support.
- Friends and relatives are free to pay them a visit at any time of the day.
- They feel respected when involved in family matters (decision making)
- Family members are always available to give them social support.

Badisang, (1992: 29) sees, home care as being of overwhelming preference over institutional care for the following reason;

- It is helpful to support each other; plan for the future together and more importantly enjoy the last days with loved ones.

Badisang (1992) further contends that, even though community home based care seems to be liked by patients and caregivers, in some cases, it has problems. He cited high prevalence of fear, stigma and shame associated with HIV / AIDS as factors prohibiting the caring for the sick at home. Secondly, the lack of knowledge on what to do and how to do it increases the fears of caring for the sick and dying at home. Thirdly, exposure to and handling of a naked body by a member of the family / community was a taboo and totally unfamiliar to the majority.

4.4 THE STATE OF SERVICE DELIVERY AND SUPPORT NETWORKS

The following table shows responses from the HIV / AIDS patients and care- givers on the state of service delivered by the CHBC team and the community at large.

The following table shows the ranking of services rendered.

SERVICES RANKED	FREQUENCY	PERCENTAGE
Excellent	0	0
Very good	0	0
Good	0	0
Fair	6	60
Poor	2	20
Very poor	2	20
Any other	0	0
Total	10	100

The table above gives us figures computed from data.

For community home based care to take off effectively, there is need for several preliminary facilities to be put in place. It needs good referral systems from the hospital to the home and vice versa. The following must be available; -

- transport to facilitate patients' movements from home to hospital for medical check up,
 - a multi professional CHBC team,
 - effective community leadership structures,
 - good service delivery,
 - food rationing to patients and
 - free communication (feedback) between patients and CHBC (Mupedziswa, 1998)
- The Baseline study for Community Home Based Care Programme for Terminally ill HIV / AIDS patients in Botswana (NACP, 31: 1996) promised to give necessary support to families with the HIV / AIDS patients. In most cases this promise has remained a theory. According to the research participants, they still face problems with transportation of patients to hospitals for medical assistance. In most cases they are transported on carts drawn by donkeys, a situation which worsens patients' health condition.

Makhene (2000:3) contends that, in most cases, caregivers feel a sense of isolation from the medical professionals who are supposed to be close to them. This results in them experiencing burnout, anger, fear, shock, depression and fatigue.

The study reveals that transportation is major problem caregivers have to reckon with. One caregiver has this to say;

" I can-not bring him to the hospital any more, transportation is too expensive and the wheelbarrow is becoming too heavy and difficult to push."

The CHBC team is said to be neglecting patients and caregivers in a way that is totally against the aims of the CHBC programme. This defeats the very purpose of the programme. According to Evian (1993: 18) teamwork provides a better approach at dealing with PLWAS, since the team consists of different professionals who will assist in addressing various problems that PLWAS encounters. The (NACP, 1996: 31-34) confirms this with the indication that, " the first most important problem which clinics believe their patients face in seeking medical attention is transportation."

The research participants pointed out that, even though there is a CHBC team, it is not that effective because health professionals never pay patients visits, and only volunteers do. This is confirmed by one of the patients when he says, " We never see medical staff in our homes, all they say is that, there is a serious shortage of staff to take home visits. The only people we always see are the volunteers who are not well trained to give us all the necessary help we need."

This is a serious problem given the fact that, most of the caregivers have never been given training on how to take care of HIV / AIDS patients. This explains why some people have the feeling that Home Based Care is governments' mechanism of getting rid of the patients. The effect of entrusting HIV / AIDS patients with untrained caregivers is that; the patients never get the care they really need while care takers because of their lack of insight in to what they are dealing with expose themselves to a lot of risks.

This is depicted in one of the caretaker's words when saying; " Why should we handle

our daughters using gloves, we do not want to look as if we have a negative attitude towards them. The fact that the medical staff have not issued us with gloves shows no need to use them."

This issue of health professionals not visiting patients in their homes indicates that; communities do not benefit from CHBC team. According to Osei - Hwedie, k. (1998:7) there is a great need for patients and families to receive counseling in the following areas; -

The HIV / AIDS patients need social support which helps to facilitate adjustment to stressful life events and in decreasing vulnerability to stress - related disorder. Social support helps one to adapt to stress and decreases emotional effects. Physical aid (verbal exchange) is as well vital in patients' life. Emotional support (empathy, esteem, and concern) as well plays a very vital role in patients' lives. Appraisal support (feed back) and informational support (education) are important in the lives of patients.

Another aspect of poor service delivery is food rationing. (70%) of the research participants pointed out that, this result from the fact that, for the registered patients suppliers orders take long time to process to enable them access the facility and in most cases they are not given vegetables and meat. This is a very a pathetic a situation since the HIV / AIDS patients' are in high need of meat and vegetables to help them to restore worn out tissues as well as heal wounds.

Most of the patients complained that health professionals take a long time to registering them for rationing. As one of the patients put it: " This is the sixth month since our names have been registered with the social workers' office and yet we have not received any food rationing. We are starving and we will end up dying of hunger and not the illness."

INADEQUATE TRAINING FOR CAREGIVERS:

The following table shows responses obtained from care givers about their care-giving role.

What training were you given in relation to your care-giving role?

CARE GIVING SKILLS	FREQUENCY	PERCENTAGE
Counseling patients	1	10
Administering medication	4	40
Feeding	2	20
Bathing	3	30
Any other	0	0

Note: figures computed from data.

Fox and Ramphael (1997) state that, the underlying factor in CHBC is that, the patient is cared for at home where he / she is in control of his / her surroundings and enjoys the primary and privacy of decision-making.

Frohlich, (2000: 48) stressed that, caregivers must be trained in a wide range of activities in order to give quality care to patients. As they are the very people who spend most of the time with patients, caregivers should be in a better position to practice basic hygiene. They should have the basic skill and initiative to deal with situations such as; -

- how to lie patients comfortably on bed
- know how to bath patients
- be equipped with counseling skills
- know the right food for patients
- have a knowledge of administering medication
- know the management of common symptoms

- be aware of protecting themselves and others from infection.

The study revealed that, most of the caretakers are not trained, and as a result most of them are not equipped with skills that will enable them deliver quality services to the patients they look after. A few of them (30 %) were given training hence they know what to do and not to. The study, as well, revealed that the problem which creates the seemingly inadequacy of trained caregivers is that a particular caregiver may be given training today, tomorrow her patient dies, that particular caregiver ceases to be a caretaker from that moment. It means that the caretakers' training needs to be a continuous thing. Most of the untrained caregivers are for those patients who have newly been diagnosed with HIV positive. The non- transferability of care givers when a patient dies and the high mortality rate of HIV / AIDS patients means that, there is bound to be the need to train more caregivers at every point in time.

CAREGIVING TO THE HIV / AIDS PATIENTS: WOMEN 'S ROLE

PATINTS		CARE GIVER SEX	PERCENTAGE
Patient	1	Woman	10
Patient	2	Young lady	20
Patient	3	Woman	30
Patient	4	Woman	40
Patient	5	Old woman	50
Patient	6	Woman	60
Patient	7	Woman	70
Patient	8	Young lady	80
Patient	9	Woman	90
Patient	10	Woman	100

Note: figures computed from data.

The study revealed that, all of the caregivers are women even in cases where a patient is a male. Some of the caregivers (70%) showed concern about this phenomenon and one of them lamented that: " In most cases caregivers are females, even when males are available to give care to their male counterparts. Men are reluctant to take up the care giving role, and this places an extra burden on women since they are as well

responsible for domestic chores." The PANOS Institute (1996), Osei - Hwedie, (1998), Stegling in Osei -Hwedie (1998), Lesetedi in Hope (1999), Squire, (1993), The Tirisano Catholic Commission all revealed the fact that men push the caregiving burden to women.

A study by Kelesitse (1998) revealed that in all the households studied, women were the caretakers, and most of them are older people. Women felt that they must play the caretakers' role, since culturally they are expected to provide care. This is so, because they have learnt to give care through the socialisation process and instinctively by bringing up their children. This is supported by the (NACP 31: 12)

4.5 THE SOCIAL IMPLICATIONS OF THE CHBC FOR WOMEN

Lesetedi in Hope (1998: 5) argued that, the low socio - economic status of women in society has contributed to the spread of HIV /AIDS and this result is worsening women's status in the society. Most women do not have resources, and this is made worse by the fact that the HIV / AIDS virus disadvantages women who have little access to resources. After infection they are forced to withdraw from the employment sector. While some women are forced to compromise their jobs in order for them to assume the caretakers' role. The study revealed that, where there are no women to take up the caretakers' role, a girl child (daughter) had to abandon her education or career in order to care give the HIV / AIDS patients.

Women's social obligation of care taking exposes them to more vulnerable position of getting infected as well. Most caregivers are ignorant of the HIV status of their patients. And since most caregivers are women, they will be exposed to infection. Kelesitse (1998) confirms that, his study revealed that one of the patients interviewed pointed out that, she contracted the HIV virus when taking care of her daughter whose HIV status was unknown.

Most caregivers expressed a sense of desperation. They are not in a state to express their experiences in words. One of them pointed out that, " My patient is paralysed, and I have to wake him up, bath him, take him to toilet and feed him. At one time due to

fatigue, I fell on him trying to help him"

The caregivers pointed out that, to care for the HIV / AIDS patients are very tiresome and frustrating. They mentioned that, they did not willingly take up the role, but rather they were obliged to do so; as morally it is expected that families with HIV / AIDS patients should take care of their ill family members

4.6 THE EFFECTS OF HIV / AIDS CARE GIVING ON CAREGIVERS' HEALTH.

Robinson et al (1995) states, the role of a chronically ill family member has been found by researchers to be very stressful to caregivers. The care-giving burden is physically and emotionally demanding. They find it difficult to maintain their own health while caring for their chronically ill family members.

According to Clark et al (1996), " burdens of giving care to a chronically family member can be overwhelming to the caregiver." Care giving is defined by these authors as the persistent hardships of caregiving.

Research participant's felt that, due to frustration, desperation, fatigue, and uncertainty of patients' condition that they experience during the care-taking role, they will end up with poor health conditions. As expressed in the words of one of the caretakers: " I have been caring for my late husband for the past two years. Now I am taking care of my two ill daughters. I do not know what to do, and I have now developed high blood pressure. At times my two daughters and I get hospitalised at the same time.

4.6 CAREGIVERS AND THE HIV / AIDS PATIENTS' NEEDS.

The following table shows the HIV / AIDS' needs as ranked according to their priority.

NEEDS	FREQUENCY	PERCENTAGE
Love and care	10	100
Medication	8	80
Financial needs	10	100
Professional support	8	80
Transport	10	100
Community support	6	60

Note: figures computed from data.

The below table shows needs of the caregivers as ranked according to their priorities.

CARE NEEDS	GIVERS'	FREQUENCY	PERCENTAGE
Care giving skills		10	100
Professional support		10	100
Financial needs		10	100
Transport		10	100
Food		6	60
Community support		7	70

Note: figures computed from data.

The research participants (caregivers and the HIV / AIDS) enumerated a lot of needs that when addressed could help caregivers discharge their services effectively, and enable HIV / AIDS patients to live positively with HIV / AIDS.

- The second need facing CHBC is financial needs. This result from the fact that most HIV / AIDS patients consult expensive traditional or spiritual healers and when their finances are exhausted they end up seeking help from hospitals and clinics. This issue is exacerbated by the fact that, the HIV / AIDS patients at terminal stage of the illness, are forced to leave their work. Their caregivers on the other hand are as well obliged to leave their work in order to assume the care-taking role. Consequently, there is no income flow to the family.

This fact is also revealed in a study by Fidzani and Atta (1996) in Francistown, Ghanzi Kanye and Lobatse.

The study revealed that, the majority of the terminally ill HIV / AIDS patients mostly sought medical attention at modern medical facilities, clinics and hospitals, but only near the end of their period of illness. Caregivers and patients confirmed that, at an early

stage of the disease, more money is spent on spiritual and traditional healers. At a terminal stage of the disease patients resort to modern medical facilities as they are cheaper and effective in treatment of the signs and symptoms. The study showed that, an average household spends 75% of its monthly income of P865, 00 on food, medication, clothing, durable consumer goods, with food and clothing taking more than half of the total monthly expenditure.

The HIV / AIDS patients pointed out that they need professional support especially counseling in order for them to open up and disclose their HIV/AIDS status to their partners children families and society at large. They expressed that they need help to plan to secure their children's future while they are still in good health. They need basic resources such as food, medical care, and employment.

The HIV / AIDS patients pointed out that their most need is to be loved, cared for and accepted by others. As this will help them to live their lives to the full. Dexter (1993) states that, patients that are given this kind of support could end up developing coping ability with the disease. Dexter further noted that the family is the place where the individual return in times of sorrow and happiness. Hogstel (1993) confirms that, the family provides individuals with a sense of identity. Patients have indicated that they need collective care giving, where the family, community, NGOs professionals, churches, government and the society should integrate their services for patient's benefits.

Mathebula, (2000: 8) argues that caregivers in most cases need professional support. This is so because they normally experience fatigue, normalising and financial concerns including strong commitment to the client. The HIV / AIDS patients caregivers are exposed to psychological distress if no psychological interventions are given especially as the illness (AIDS) is at its terminal stage. Psychological intervention is one of the needs that caregivers need to reduce psychological distress.

Fidzani et al (1996) state that, the lack of professional support to the CHBC programme caregivers is a major hindrance towards quality service delivery. The same study identified

that caregivers at hospitals deliver better quality services to patients than those of CHBC programme. This is the case because CHBC programme caregivers are not equipped with all the necessary skills needed to deliver quality services. The support and visitation of health workers was identified as being very limited or none at all.

This is confirmed by Ngwako's findings which explored caregivers needs in a convenient sample of 22 HIV / AIDS patients caregivers in Botswana. The descriptive qualitative study revealed that caregivers do not receive any support from health professionals. 32% of the caregivers indicated that, health professionals had never visited them since the patient was disclosed from hospital. (Ngwako, 1994).

Ngwako and Fidzani's studies are very important in as far as the CHBC programme is concerned, these studies show us that the CHBC programme is not "living up to the NACP objective which is to increase access of AIDS families to skilled professional services on a regular basis." And this will not achieve Reinhard's (1994) finding that through professional support caregivers could cope sufficiently with their care - giving role.

4.7 THE HEALTH SYSTEM: POLICY - MAKERS (COUNCILLORS) AND CHBC TEAMS

VIEWS TOWARDS HIV / AIDS

The research participants (90 %) felt that the rapid increase of HIV / AIDS in the village might be a result of the close proximity of the village to the big towns (Lobatse and Gaborone) as well as the village's nearness to South Africa (Mmabatho and Mafikeng).

Lesetedi, in Hope (1998: 51) "there is a strong link between poverty and the spread of HIV / AIDS. The low economic and social status of certain groups in society has contributed to the rapid spread of the virus. Botswana has experienced rapid economic improvements but despite this impressive development records, the persistence of income inequality and poverty among women remain important areas of concern. Income levels are generally lower among female - headed households."

Research participants as well felt that, the fact that the HIV / AIDS epidemic is most

prevalent among women is a result of the uneven power distribution between men and women. The feeling is that women do not have a saying when it comes to sex issues. This is confirmed by Lesetedi in Hope (1998: 58) who state that, women find it difficult to negotiate for safe sexual practices with their partners because sex is a taboo subject even between husband and wife. A woman who discusses sex issues openly is perceived as ill - mannered and promiscuous. In most cases if not all, men are the ones who decide what to do, how to do it and when to do it, and women are not to question the decision."

The rapid spread of the HIV / AIDS disease is as well associated with the fact that, in most cases both sexes have a negative attitude towards condoms. Because it is said they reduce sexual pleasure, and a person who uses condoms is compared to a person who would eat sweets in their wrappers. Participants also pointed out that, men are freer to buy condoms with out being questioned unlike their women counterparts. Their husbands and boy discourage women - friends to keep condoms in their houses as a woman who does so is taken as a prostitute.

The research participants (80 %) have a feeling that, by at the time the government started to respond to the HIV / AIDS epidemic most of the stakeholders were not consulted. Hence the rapid spread of the virus in the country Goodhope inclusive, in spite of the fact that government tried its utmost to contain the situation. This is confirmed by Molutsi in Hope (1998: 14) when stating that, when Botswana started to respond to the HIV / AIDS problem, NGOs and districts were not generally involved in the planning processes AIDS activities at the national level. There was a lack of commitment and involvement by senior administrators from key ministries, politicians, communities and leaders. Further information, education, communication (IEC) coverage for priority target groups was low because strategies and messages tended to be general and not targeted and finally there was inadequate counseling since consoling sectors apart from the health sector had not been adequately involved.

4.8 POLICY MAKERS AND CHBC TEAM'S VIEWS TOWARDS CHBC PROGRAMME

The reviewed literature reflects that, the most viable option for providing care to the

terminally ill persons is CHBC programme. The participants of the study as well share the same sentiment. They feel that, the terminally ill will only feel relaxed in a normal environment with relatives providing care unlike in a hospital set up where patients are in an unusual environment and cared for by unfamiliar people to the patients (nurses)

" The CHBC programme is a very effective tool of caring for the terminally ill patients. But in our country, the programme was imposed on lower officials by top policy makers, ministers, members of parliament and top civil servants) we were not even consulted to make contributions towards its formulation. As a result the programme exhibit loopholes some emanating from staff shortage, and it is even worse with the nurses leaving the country for greener pastures in the United Kingdom. The programme experiences shortage of resources such as transport and many others."

The research participants (90%) feel that, the programme does help decongestion of hospitals as in most cases because hospitals fail to cope with the ever increasing numbers of the HIV / AIDS terminally ill patients. Most policy - makers' feeling was that, in traditional African communities family members care for family members who are ill and so the concept of CHBC as well commit communities to care for their sick members. It instills the spirit of caring for the loved ones. This is the point because CHBC encourages and gives people last chances to care for their dying patients.

4.9 POLICY - MAKERS AND CHBC TEAM VIEWS TOWARDS CHBC PROGRAMME SERVICE PROVISION.

The following table shows responses received from the Policy makers (councilors) and the CHBC team about the pressing needs of the CHBC programme.

The CHBC Programme pressing needs.

CHBC NEEDS PERCENTAGE	PRESSING	FREQUENCY	PERCENTAGE
Shortage of staff		9	25
Lack of comm. Support		6	17
Lack of finance		5	14
Little training-caregivers		8	22
Shortage of transport		8	22

Note: figures computed from data.

Most participants (90 %) share the sentiment expressed above that, communities are obliged to provide care to their terminally ill patients, but that conditions under which communities are operating are not conducive at all. Many of them live in abject poverty and have no access to resources. According to Lesetedi (in Hope sr.1998: 47, PANOS Institute, 1992: 66) " While the poorest of the poor have been notoriously hard to reach for development purposes, it has not been hard for the virus to reach them."

Lesetedi in Hope1998, Sewpaul1998, Rollins1999, and Hayson1998 confirm that this is the case because the poor are poorly educated and have less knowledge and awareness of health practices and are therefore less likely to protect themselves from HIV / AIDS infection. Their poor health status could be linked to their low nutritional status. Good nutrition is critical in the fight against HIV / AIDS, as a well balanced diet has shown to help to boost the immune system to fight the virus. As pointed out by Grief and Golden, (1994: 68) nutrition is the cornerstone of good health. In the light of the above, the CHBC programme cannot be as effective as it is meant to be when food package mentioned in the CHBC NACP (1998: 14) are not actually supplied to patients.

It is paramount that nutritional considerations begin when a patient is first diagnosed as HIV / AIDS positive. Casey (1997: 8) contends that, weight maintenance should be a critical part of the dietary management goals. There is the need to maintain nutritional status and to slow or reverse weight loss.

Both the policy makers and the CHBC team concurred with the HIV / AIDS patients and caregivers that, there is a problem with food rationing. The problem was said to be due to shortage of the welfare staff as well as the unreliable food suppliers. However, there was a concern that some families do not want to register their patients for food rationing as this families do not want their patient to be associated with the HIV / AIDS disease. It was pointed out that some families hide their patients either at the cattle post or the lands so that people can- not see them. This problem goes back to the issue of negative stigma towards the HIV / AIDS patients.

The participants pointed out that, many families with HIV / AIDS patients are experiencing economic problems, and this was attributed to the fact that, many families consult expensive healers from the initial stage of the disease and when the disease worsen they resort to medical facilities. The other reason was that, as an HIV / AIDS patient becomes terminally ill he / she is forced to leave employment. The same thing happens to the caregivers of the HIV / AIDS patients. It could be argued that, HIV / AIDS brings about a disequilibrium in the affected families since all energies are directed to providing care and not in obtaining resources for the survival of family members.

The participants feel that CHBC programme could become an effective mechanism for caring for the terminally ill patients if only it is furnished with the necessary facilities. It is felt that currently the programme is plagued by many problems, which act as a hindrance towards quality service delivery. Shortage of staff is a very pressing issue as many professional nurses are leaving the country for "greener pastures" in the developed countries. This results in one HIV / AIDS coordinator dealing with AIDS activities of a whole sub - district and its catchment areas, a scenario which under normal circumstances, cannot be allowed. The programme is facing a shortage of social

workers, dieticians, physiotherapists, and many other professionals. This explains why in most cases the HIV / AIDS patients and their caregivers get the impression that they are not being visited regularly.

Research participants indicated transportation of patients to the hospital as one of the problems facing the programme. This continues to be the problem despite the (NACP 30: 17) recommendations that transport and staff will be increased in every hospital and clinics.

The other problem, which kept recurring in the study, is the inadequate training of caregivers. There was a general consensus that, the HIV / AIDS patients' care is solely the responsibility of caregivers. However they expressed their disappointment in that, in most cases caregivers have not been trained for the care-giving role. This was taken to be one of the key problems facing the programme. According to the participants this is the case because caregivers do not have time to attend workshops and seminars where they could be trained on the care-giving role. However the general consensus was that, caregivers will be trained for them to be able to recognise some symptoms, know how to treat them if possible and if not refer patients to the hospital.

The participants showed a great concern that, due to the nature of the HIV / AIDS disease, there is a likelihood for the caregivers contracting the disease and dying before their patients as since the majority of them do not take precautionary measures. There was a general consensus that, the caregivers' training should be standardised so that they end up with a common understanding of what is expected of them for the care-giving role. The participants felt that training of caregivers coupled with professional support during the care giving period is very vital. In order to overcome caregivers trauma, pain and frustrations, since they are dealing with a very sensitive disease.

THE CHIEF AND HEADMEN'S VIEWS TOWARDS HIV / AIDS I

The village chief was concerned about the rate at which the HIV / AIDS virus is spreading. He attributed this to the villages' close proximity to big towns and South

Africa. He also pointed out that, culturally, women are brought up in a way that they should be submissive to their male counterparts and that they are not supposed to have a say when it comes to sexual affairs. He gave an example of cases where women can not tell their boyfriends or husbands to use a condom when it comes to intercourse. The chief understood very well that HIV / AIDS is caused by a viral infection. He pointed out that HIV / AIDS keeps a rapid pace despite the "kgotla" meetings always held to give the community information on the causes of HIV / AIDS. He believes that people who have a different view on the causes of HIV / AIDS apart from the real cause are the ones who are misleading some of the people in the community.

Out of the interviewed five Headmen (3) of them were of the opinion that HIV / AIDS is caused by witchcraft and "boswagadi" (when a widow or girlfriend / widower or boyfriend do not under go sexual cleansing after the death of a spouse). The remaining two held the belief that HIV / AIDS is caused by a virus. Those who hold the belief that HIV / AIDS is caused by witchcraft and "boswagadi" were of the concern that unless people stop bewitching others and sexual cleansing is taken seriously HIV / AIDS will wipe out all the people, whilst the remaining two who see HIV / AIDS being caused by a virus were concerned that unless people change their promiscuity HIV / AIDS will keep spreading fast.

4.10 THE SPIRITUAL HEALERS AND TRADITIONAL DOCTORS' VIEW TOWARDS HIV / AIDS.

Out of the five interviewed spiritual healers (3) of them were of the opinion that HIV / AIDS is a punishment from God to those who engage in extra-marital affairs, and caused by witchcraft. They believe that if people could stop bewitching others and engaging in sexual practices out of wedlock then HIV / AIDS will be dealt away with. These spiritual healers were of the opinion that they can cure the HIV / AIDS virus, but when asked by the researcher to show those people whom they have cured they failed to do so. The remaining (two) spiritual healers were of the view that HIV / AIDS is caused by a virus, and that the disease is incurable. They pointed out that they usually

preach to their congregations about the causes of HIV / AIDS and that they should be careful so as not to contract the disease. Out of the five interviewed traditional doctors two of them were of the opinion that HIV / AIDS is caused by a virus and the remaining three said it is caused by witchcraft and "boswagadi."

4.11 THE CHIEF AND HEADMEN'S VIEWS ON CHBC PROGRAMME SERVICE DELIVERY.

The interviewee praised CHBC programme for catering for the terminally ill HIV / AIDS patients. Some of the respondents pointed out that since HIV / AIDS is incurable, the only service they render to the HIV / AIDS patients is visiting them and their families in order to give them social support. As village leaders, the respondents were concerned with the fact that the community is still reluctant to volunteer in the CHBC programme. They mentioned that only a few people have volunteered and had fear that with time the volunteers will drop off if not paid. The respondents expressed their concern for the ever increasing shortage of staff in the Goodhope sub district, and said this contribute to the inadequacy of the CHBC programme as only a few not well trained volunteers are the ones carrying home visits.

4.13 THE TRADITIONAL DOCTORS AND SPIRITUAL HEALERS VIEWS TOWARDS CHBC PROGRAMME SERVICE DELIVERY.

The respondents shared the same sentiment that, CHBC is the only best way of caring for the terminally ill patients as hospitals cannot cope with the ever increasing numbers of the HIV / AIDS patients. They however showed a concern that the Goodhope sub district experiences a high shortage of staff and this results in the inadequacy of the programme. The respondents mentioned that the few volunteers are the ones who in most cases carry out home visits. The respondents mentioned that they help the patients by paying them visits. The traditional doctors indicated that they at times give patients some herbs to drink while spiritual healers give holly water to the patients. The interviewee pointed out that when treating patients, they do not use the same equipment (raiser blade, knives) because they are well aware of the fact that HIV / AIDS is infectious.

4.14. SUMMARY

This chapter discussed the findings of the data collected from the research participants, (HIV \ AIDS patients, caregivers, Policy makers, Health professionals, the village chief and headmen). The findings showed that there is need for more education on HIV \ AIDS modes of transmission. This is the case because half of the HIV \ AIDS patients, their caregivers, some traditional healers and spiritual healers stated that HIV is caused by either witchcraft or "boswagadi". The researcher's observation is that, most of the respondents with no or low education attributed the causes of HIV to witchcraft and "boswagadi" while all the health professionals Policy makers the village chief understand very well the HIV causes. This is a group of people with secondary education hence the understanding of the causes of HIV.

The study revealed fear of disclosure of ones' HIV \ AIDS status. The majority of respondents indicated that, this is so, because once a person discloses his \ her positive HIV status then He \ She would be subjected to stigma of rejection and would be discriminated against. This fear of disclosure issue leaves the government with a lot to do in order to do away with it.

When asked to share their views on CHBC, all the respondents submitted that they prefer it to institutional care. Their main worry was the programme's poor service delivery and this they attributed to shortage of resources, (manpower, food, transport and bedding). The other issue, which came to light, was that, in most cases if not all, care giving is a women's role, in some cases forcing them to leave their work in order to become full time caregivers. In the absent of a caregiver, a young lady is forced to leave school and take up the responsibility, a thing, which dooms a girl child's future.

The other burning issue, which came up, was the fact that, even though volunteers and caregivers are expected to perform to the utmost, they have not been equipped with the necessary training in order for them to deliver quality services. The main worry here is that, caregiving coupled with the fact that caregivers are not told of their patients' HIV \

AIDS status can lead to one being infected. The other concern raised by the research participants is that, in most cases women do not have a say when it comes to sex issues. A thing, which leaves most of them, infected because if a man does not want to use a condom they just keep quiet even if they dislike the idea. In light of all the issues discussed above, it is very clear that the CHBC programme is theoretically sound but practically not.

CHAPTER FIVE

5.1 INTRODUCTION

CONCLUSION AND RECOMMENDATIONS

This chapter presents summary and recommendations of the study. The central focus of the study was to explore how the CHBC policy for PLWAS is being implemented in Botswana. It is also an attempt to find out whether the CHBC policy is achieving its intended impact on the PLWAS and their families and if not, what the obstacles to the effective implementation of the policy and the programme are. The study as well sought to find out whether various stakeholders in CHBC programme are playing their requisite roles to ensure quality service delivery.

5.2 Discussions and Conclusions

Interviews were conducted with a sampled number of ten respondents, each from HIV / AIDS patients, care givers policy makers the CHBC team, five respondents of headmen, spiritual and traditional healers and the village chief.

The study sought to test the following hypothesis: -

CHBC programme for PLWAS is not effective because of;

- Shortage of resources (health professionals, transport, food and funding) in giving support in the following; - (psychological, medical,

spiritual material and social).

- The unexpected (low) support it received from the communities.
- The understanding of and attitudes to HIV AIDS by many of the patients
Caregivers and some community members.

The three hypotheses were to be confirmed or refuted by accessing information to answer the following key questions; -

- What are the problems hindering quality service delivery of the CHBC programme?
- How much support do you get from the various groups in the community?
- Do you consider the CHBC programme effective? If not what do you take to be the hindrances towards its effectiveness.
- How do you hope service delivery could be improved?
- What do you understand to be the modes of transmission of HIV / AIDS?

The effectiveness of the CHBC programme in the Goodhope sub - district was measured against:

- NACP, 30, (1996) Operational Guidelines for PLWAS in Botswana since the document is a framework for all CHBC activities in Botswana.
- The Network Theoretical framework, which provided the conceptual base for this study.
- Lessons from CHBC as practiced in other countries as portrayed by the review of international literature.

The policy document spelt out the following conditions as necessary for the efficient operation of the system;

Every stakeholder in the CHBC programme (members of the CHBC team clinic hospitals and the community at large) has been given a role to play. A CHBC programme package consisting of the necessary materials to be used to help the patients during their stay in the home has been proposed to be availed to each and every HIV / AIDS patient and the care givers. A package of some medication which is vital for the HIV / AIDS patients health during their stay at home has been proposed to the CHBC team comprising of doctors, nurses, social workers, Health Educators, dieticians, families, non - governmental Organisation village committees and the community members, politicians, headmen and volunteers.

The Network Theory that provided the conceptual framework for an ideal CHBC programme stipulates the need for teamwork or partnership of requisite stakeholders each performing his/her duties efficiently. The theory stresses a strong organic relationship among all members of the team, as a necessary and sufficient condition for its success. In the case of this study, doctors, nurses, social workers, physiotherapists, nutrition officers, non - governmental organisations, families, community leaders, community committees and the community at large are to join forces together to provide care for PLWAS. Each member of the team complements the others and so the ineffectiveness of any single role player cripples the whole team.

The findings of this study confirmed the three hypothesis of the study. The research question, which wanted to find out whether the CHBC programme in the Goodhope sub - district is effective, overwhelmingly recorded negative responses. The first hypothesis, which assumes that, CHBC programme for PLWAS is not effective because of shortage of resources, was confirmed by the findings. What emerges glaringly from

the findings is that: The CHBC programme in the Good-Hope area of Botswana is ineffective because of the serious inadequacy of resources, particularly manpower, transport and funds.

Secondly, the programme is not effective because it has not been able to elicit the requisite support from the community. The manpower problems revealed by the findings can be summarised as follows:

- Unavailability of doctors nurses social workers, volunteers, and caregivers.
- Inadequate training for care- givers.
- High volunteer and staff (nurses) turnover.

The problem with this manpower shortage is it disturbs the teamwork concept on which the CHBC system is based. Gaps are created in the Teamwork machinery as spelt out by the Network Theory and the chain of services that are expected to complement each other and culminate into a holistic package of services for the PLWAS does not materialise. Thus adequate presence of all role players of the CHBC programme as spelt out by the policy document is a non-negotiable condition for the success of the programme.

The transport problem is a huge stumbling block in the way of the programme. This is because the success of the programme necessitates frequent contact between members of the team and the patients under their care; frequent movements of patients to hospitals and clinics and movement of supplies from source centres to patients. The policy document underscores the importance of a healthy transport system in the effective implementation of the programme. In the spirit of the Network Theory easy mobility among members of the network is a necessary condition for the network to operate coherently. Transport is therefore the life- line of the CHBC programme.

Inadequate funding is another major problem militating against the effective operation of the programme. Its effects on the programme are:

- Lack of supplies to patients.
- Inability to provide financial rewards to volunteers.
- Improper handling of food rationing component of the programme.
- Inability to train / employ qualified personnel.
- Inability to provide transport facilities

Funding can justifiably be called the life-blood of the programme because it dictates what type of resources can be available and in what quantities.

The absence of community support for the programme is another problem that raised its ugly head in the findings. This arises from the fact that volunteers are not being rewarded despite the high risks involved in the job and the stigma attached to the disease.

The fact that most of the respondents (HIV / AIDS) patients, caregivers (spiritual and traditional healers) hold a wrong belief about the modes of transmission of HIV / AIDS as well poses a serious problem to the effectiveness of the CHBC Programme. This is a problem because more and more people would be infected with HIV virus if people do not understand fully the actual causes of the disease. This lack of understanding of the disease by some research respondents is proved by the fact that HIV / AIDS modes of transmission were attributed to either witchcraft or "boswagadi."



These formidable barriers have rendered the programme grossly ineffective; thus confirming the three hypotheses of the study. That the CHBC programme in the Good-Hope area in Botswana is ineffective because of the serious inadequacy of resources, particularly, manpower, transport and funding; that the programme is also failing to achieve its

requisite results because of lack of support from members of the community and that people still hold wrong beliefs about HIV / AIDS especially.

5.3 Recommendations

The conclusion arrived at indicates that radical remedial measures have to be implemented to inject life into the programme. The following recommendations are necessary for resuscitating the programme.

The HIV/AIDS situation in Botswana is analogous to a war scenario. Our opponent --HIV/AIDS--is seriously winning the war, --- vandalising our youth, killing large numbers of our working population, increasing the enrolment of orphanages and turning a teeming number of children into "parents".

Like all war situations extra-ordinarily radical measures are needed to complement the normal procedures of doing things. It is in this light that the following recommendations are made;

- To address the manpower inadequacies, the government must introduce a crash programme to train special medical personnel to handle the HIV/AIDS patients. They can be called AIDS technicians. These personnel must be given basic training in medical science, nursing, social works and other disciplines necessary to handle the problems of AIDS patients to a certain level. The duration of this training must be very short but long enough to enable the candidates cover and assimilate the required professional standard. Such personnel will regularly visit the patients and their multi-disciplinary outlook will make them versatile and of high utility to the patients. The

availability of such all- purpose personnel will relieve the pressure on doctors, nurses and other medical personnel who are already in short supply.

- Secondly, all uneducated citizens above the age of twelve in the rural areas must be made to attend and obtain a certificate in an education and training programme on HIV/AIDS. This course has to cover awareness issues, how to handle patients, and how to prevent the disease from spreading. Such a programme will reduce the need to organise special training for caregivers because it will create reservists to fall on in every home when the disease strikes.
- The government must not relent on its efforts to increase AIDS awareness in the country. Research must be carried out to find out the most appropriate methods to elicit AIDS- conscious behaviours and empathy; rather than stigmatize them.
- The communities must be made to understand their roles in this AIDS war situation. Traditional rulers and community leaders must be part of the CHBC planning committees at all levels. The communities must be assigned specific responsibilities --- establishment of community gardens to supply vegetables to patients their caregivers and volunteers; the assignment of volunteers to patients, building huts for patients or the weeds around houses of patients. Participation in this type of community services must be compulsory to all able-bodied members of a community.
- The acute transport problem crippling also needs a radical solution. The armed forces of the country can contribute their fair share to this war by providing transport on specific days to the patients. This must be planned in such a way that all CHBC teams are assigned a number

of army vehicles to facilitate the transportation of patients, team members, supplies and other relevant items.

- Businesses must also be made to contribute to the CHBC programme by paying a certain percentage of their profit to the programme. A part from this tax, businesses must be encouraged to make humanitarian donation to the programme.
- The government should see to it that CHBC programme is allocated enough funds to carry out the programmes' activities. Such as provision of food to the infected, improve materials condition, transport and incentives for volunteers in order to keep them in their volunteer role. The caregivers should be given incentives considering the fact that all of them are not working and are performing a very tiresome work. The government should not rely mostly on funds provided by the International Organisations as they could withdraw at any time. Hence the government should be seen to be taking an active role and showing commitment in caring for its citizens.
- Food shortage is one of the problems facing the programme and in most cases this emanates from unreliable food suppliers. To address the problem, social workers should make it a point that food suppliers are closely supervised, to ensure that patients are given the right food at the right time. An increase in social workers will as well help to do away with the long patient's registration processes
- To address the negative attitude towards the HIV / AIDS patients by the community, there is need for HIV / AIDS education to continue up until a point in time when people will master the causes of the HIV / AIDS disease. Traditional doctors and spiritual healers together with

people who still hold to the believe that HIV / /AIDS is caused by boswagadi, punishment from God and a result of no sexual cleansing need to be informed on the actual causes of the disease. There is great need for the government to see to it that all traditional healers who do not give the community the right information on HIV / AIDS should be not allowed to practice. Those who claim to be capable of curing the disease should as well denied the right to give patients treatments because they end up depriving people of their properties and making the government responsible of these families poverty. In order to have a wide coverage HIV / AIDS education is to be carried out in primary secondary and tertiary institutions of learning.

- To address the negative stigma that the HIV / /AIDS patients and the caregivers attach to the patients, there is great need for the HIV / AIDS patients and caregivers to be made aware of the causes of the HIV / AIDS epidemic, in order to minimise further infection. Caregivers must be well informed of the disease their patients are suffering from so that they engage precautionary measures during their care-giving role. The HIV / AIDS patients need to be counseled as a way of empowering them in order to help them to live positive with the disease. This will empower them to a point that they will do away with the negative stigma that they attach to themselves. A situation, which ends up with some of them, committing suicide and others hiding themselves from the rest of the community. Care givers and the community members should be given enough HIV / AIDS information so that they help in counseling the patients instead of attaching a negative stigma to them.
- The government should see to it that more education on HIV / AIDS is expanded and taken to communities in a very understandable

language. There is great need to educate the public on the HIV / AIDS modes of transmission in order to do away with the idea of saying HIV / AIDS is caused by witchcraft. The public should be consulted on how best the HIV / AIDS related issues could be best addressed, by so doing the public will feel that they are part and parcel of the whole thing. This will make people feel that the HIV / AIDS issues are not imposed on them but instead they will feel respected when implementing the policies formulated by them. The involvement of the public in formulating and implementation of this kind of policies will as well do away with the ever-increasing problem of negative stigma towards HIV and AIDS.

- To address the problem of untrained caregivers, there is need for them to be trained in their care-giving role in order to equip them with the necessary skills. This will benefit the HIV / AIDS patients as they will be provided with the relevant care, and the care givers will as well benefit in the sense that they will be in a position to handle the infectious and fatal disease in a more careful way and will not be infected. Unlike the current situation where the untrained caregivers are at risk of contracting the disease, as they are not using precautionary measures. A situation, which has been, reported leading to the care givers dying before their patients. The caregivers training should be standardised and designed for various settings, rural and urban areas should have different training designed to meet different context within which CHBC programme is practiced.
- The caregivers to the HIV / AIDS patients are to be supported by health professionals as well as the community at large in their day-to-day delivery of services. This will ensure that both the caregivers and the patients benefit from all members of the CHBC team. The

caregivers need to be given all the necessary information on HIV / AIDS in order to minimise further HIV / AIDS spread. Training of care givers will as well save them from frustrations, burnout, fear of the unknown and depression they experience from care taking a very pathetic and disheartening disease such as HIV / AIDS. Curriculum innovations should be made stressing the importance of the professional nursing support to PLWAS and their families.

- There is a strong need of communication between patients, caregivers and the health professionals. This will be of great benefit to all the parties and lastly quality services will be put in place.
- CHBC programme requires a comprehensive approach. Which entails provision of a continuum of services. This means a CHBC service structure ranging from management and treatment of the infected, to the prevention and awareness. The strategy considers that isolated efforts at management and care of the infected can not be effective if these are not coupled with prevention and awareness, and that isolated efforts will be counterproductive in the fight against HIV / AIDS spread. Relevant parties (stakeholders), in the formulation of policies that are meant to address the HIV / AIDS problem.
- There is a need for further research to be carried out in this field in order to continue to look for more better ways of improving services for the HIV / AIDS patients. This study revealed some issues, which hinders effective service delivery of PLWAS. Such as fear of disclosure, social ostracism of PLWAS, and societies negative attitudes towards the HIV / AIDS patients, and the superstitious beliefs on the HIV / AIDS modes of transmission need to be addressed seriously in order to minimise the spread of the HIV / AIDS disease.

BIBLIOGRAPHY

Bailey, K (1987): Methods of Social Research. Macmillan, London.

Badisang, B. (1996). Living with AIDS in the Community. Botswana: Macmillan Botswana Publishing Company. Pty ltd.

Beedham , H. and Wilson – Barnett , J. (1995) . HIV / AIDS care /: consumers' views on needs and services. Journal of Advanced nursing, 22, 677 – 686.

Brown, M.N. and Powell – Cope, (1991). AIDS Family CareGiving: Transition through uncertainty. Nursing research, 40. (6 / 338 – 344.

Burns, N. and Grove, S. K. (1997), The practice of nursing research: conduct, critique and utilization. Philadelphia: W. B. Saunders.

Challis, L. (1990). Organising Public Social Services. United Kingdoms: Longman Industry and Public Service Management.

Clark, M. AND standard, P. L. (1996). Caregivers burden and structural family model . Family and Communities health . 18 (4). 58 – 66.

Darling, V. H. and Rogers, J. (1986). Research for practicing nurses: Themes in nursing. London: Macmillan.

Doxter M.and Harbert W. (1989). The Home Help Services London: Tavistock Publications.

Economist, (1996). February. 10.

Evian, C. (1993) Primary AIDS Care: A practical guide for Primary Health Care in the Clinical and Supportive Care of people with HIV / AIDS, Jacana, Johannesburg.

Fidzani, N.H. and Atta, J.K. (1996). Baseline for the CHBC programme for terminally ill HIV / AIDS patients in Botswana NACP 31. AIDS / STD Unit Ministry of Health. Gaborone, Botswana.

Field, P.A. and Morse, J. M. (1985) Nursing research: Application of qualitative approaches. London: Groom Helm.

Fox, DM and Raphael, (1997) Home Based Care for a new century, Blackwell, Oxford.

Frohlich, J. et al (2000). HIV / AIDS Home-Based Care. Gaborone: Macmillan Botswana Publishing Co. (pty) Ltd.

.Government of Botswana (1996). National AIDS Control Programme no.2 Gaborone. Ministry of Health Government Printer.

Green , L . W . and Ottonson , J. M . (1994) . Community health (2nd ed). Chicago: Mosby.

Hans , Jo (1998) AIDS and AIDS Risk patient care , Britain : Unwin Bros .
Williams , E. I . (19989). Caring for elderly people in the community (2nd ed). London . Chapman and Hall.

Health , Ministry of (1998) , Botswana National Policy on HIV / AIDS. (Revised Version). Gaborone : Ministry of Health , September.

Hegstel M.B. (1983) Management Personnel in long term Care. United Staes of America : Prentice – Hall International.

HIV / AIDS and the Law : A resource Manual 1997 , The AIDS law Project and lawyers for Human Rights , Johannesburg.

Hogstel . M . B . (1983) Management of personnel in long term care . United Staes of America . Prentice Hall.

Hope Sr. K.R. (1999) AIDS and Development in Africa. United States of America: The Hathworth Press.

Kaye , W. (1992). Home Health Care. United States of America : Sage Publications , Inc.

Lachman, S. J (1997) Heterosexual HIV / AIDS as a global problem: Towards 2000, The Natal Witness printing and publishing, Pietemartitzburg.

Leininger , M . M. (1985) Qualitative research in nursing, New York : Grune and Stratton Inc.

Lesetedi , Gwen N. (1999). “ HIV / AIDS and the status of women in Botswana”. In Hope Sr.Kemp Ronald (ed) AIDS and Development in Africa : A Social Science Perspective

Lithosphere T. (1996). AIDS References Manual. United Kingdom: Nam Publications.

Lund,F(1996) The committee report on child and family support, Government Printer, Pretoria.

Lynam , J. m . (1995) . Supporting one another : The nature of family work when a young adult has cancer . Journal of Advanced Nursing , 22 , 116 – 125.

Mail and Guardian, 30May1997, Johannesburg.

Mathebula , (2000) Experiences and needs of Caregivers Regarding CHBC for AIDS patients in Francistown. Unpublished masters thesis. University of Botswana, Gaborone.

Mbatha – Ndaba , R . D . (1998) . family home caregiving : knowledge available to caregivers in the village of Mogoditshane, Botswana. Unpublished masters thesis . University of Botswana, Gaborone.

Molatole T. (1998) AIDS patients Discharged on CHBC Programme: The Nature of Social Support Resources being offered to them. Unpublished masters thesis. University of Botswana , Gaborone.

Morse , J . M . (1991) qualitative research : A contemporary dialogue . London : Sage Publications.

Mosiemang , Bosisiwe (2001). " Research Throws light on AIDS in Botswana " Mmegi / The Reporter , January 19 – 25.

Motsa , S.M. (1999) . Professional. Support available to caregivers of people living with HIV / AIDS. The case for Molepolole. Unpublished masters thesis. University of Botswana. Gaborone.

Mthembu, P (1998) " A positive view," Agenda: Empowering women for gender equity, 39:26-29.

Mupedziswa , R. (1998) AIDS in Africa : The Social Work Response . Journal of Social Development in Africa , Harare.

National AIDS Coordinating Programme, (1996) Baseline Study for The Community Home Based Care Programme For Terminally Ill HIV / AIDS Patients In Botswana. Botswana Government Press.

Ncube et al (1999) HIV / AIDS home – Based Care Guide. Botswana Government Press.

Ngwako S.K. (1994). District Needs Assessment of AIDS, Caregivers in Kgatleng. Gaborone : University of Botswana.

Osei – Hwedie (1998) HIV / AIDS Policy Implementation : Home Based Care as a Policy instrument in Botswana. Journal Social Work / Ma

Osei – Hwedie K. (1994) “Informal Social support and Formal Provision of Social Services “. Journal Social Work / Maatskapline Work/ Volume 30 / 2)

Phindela , T. (1998).HBC : Sharing the challenge. A paper presented at the Global Summit : Botswana 26 – 30 , Julj , 1998. Unpublished.

Piccard J.B. (1998) . Introduction to Social Work , United States of America : The Dorsey Press .

Polit , D.F. and Hungler , B. P. (1995). Essentials of nursing research: principles and methods , 5th ed. Philadelphia : Lippincott – Raven Publishers .

Polit , D. F. and Hungler , B.P. (1995). Nursing Research and Principles and methods , 5TH ed. Philadelphia : Lippocott co.

Powel – Cope , G . M . (1994). Family Caregivers of people with AIDS : Negotiating partnership with professional heath careproviders . Nursing Research 43 , (6) : 324 – 330.

Reinhard , S. (1994) . Living with mentalillness : Effects of Professional Support and personal control on Caregivers burden. Journal of research in psychology and health. 17. 79 – 88.

Republic of Botswana (1997) Botswana HIV and AIDS. Second Medium Term Plan (MTP11) 1997 – 2002). Gaborone ; Ministry of Health.

Republic of Botswana (1996) Community Home Based Care for People living with AIDS in Botswana. Operational Studies. Gaborone: Ministry of Health.

Republic of Botswana 1998 , Evaluation of the Community Home Based Care Project (Molepolole and Tutume Sub – District). Gaborone : Ministry of Health) National AIDS Control Programme , February.

Robinson, M. and Steele , D. (1995). The relationship between health and Social Support in caregiving wives as perceived by significant others. Journal of Advanced Nursing , 21 , 88 – 94.

Sewpaul, V and Rollins, N (1999) Operationalising developmental social work: The implementation of HIV / AIDS project, Social Work/Maatskaplike Werk 35(3):250-263.

Sims R. et al (1992) , Terminal Care for People with AIDS. Britain : Holder and Stoughton.

Skidmore , R . et al . (1991). Introduction to Social Work. United States of America : Prentice – Hall , Inc.

Stanhope, M. and Lancaster , J. (1996). Comn. Health nursing . Promoting health of aggregates , families and individuals. New York : Mosby.

Stegling , Christine (2000) , “ Current Challenges of HIV / AIDS in Botswana “. Paper Presented at the Social SCIENCE AND society Seminar Services. Gaborone : University of Botswana , Department of Sociolgy ,February 3.

Squire (1993)

Strauss , A . and Corbin , J. (1990) , Basis of qualitative research : grounded theory procedures and techniques. London : Sage Publishers

Turner , H. A., Catania , Gagnon , (1994). The Prevalence of informal care giving to persons with AIDS in the United States of America , Caregivers characteristics and implications. Social Sciences Medicine. 38. (4) 1543 – 1552.

UNDP. (1998) Poverty and inequality in South Africa: Report prepared for the Office of the Executive Deputy President and the Inter-Ministerial committee on poverty and inequality.

UNECA (1996). Report of the Social and Economic Situation in Africa . Addis Ababa. United Nations Economic Commission for Africa.

Webb , D. (1997) HIV and AIDS in Africa , University of Natal Press , Durban.

WHO (1993) . AIDS home care hand book Geneva : WHO.

Whiteside, A (1999) South Africa's 1998 survey shows results show no let up.
AIDS Analysis Africa 10 (1):11-12.

Williams, E.I. (1989). Caring for elderly people in the community (2nd ed).
London. Chapman and Hall.

Wilson , H . (1985) Research in nursing . Menlopark , CA : Addison – Wesley.
UNECA (1996). Report of the Social and Economic Situation in Africa (1996).
Addis Ababa. United Nations Economic Commission for Africa.

Woodside , M. et al. (1998).An introduction to Human Services. United States of
America: Brooks / Cole Publishing Company.

World Bank (1991). World Development Report 1991 : The challenge of
Development. New York : Oxford University Press.

QUESTIONNAIRE FOR CARE-GIVERS

1. What are the range of services that are provided by the CHBC team?

2. How can you range the importance of these services?

- | | |
|---------------|---------------|
| (a) very good | (d) very poor |
| (b) good | (e) poor |
| (c) fair | (f) any other |

3. If provided services are poor, suggests ways to improve them.

4. What is the criteria used to get services?

- | | |
|----------------------------------|-----------------|
| (a) pay for services | (d) no response |
| (b) first come first serve basis | (e) any other |
| (c) queue for services | |

5. How often does the CHBC team visit you?

- | | |
|----------------------|--------------------|
| (a) once a week | (d) thrice a month |
| (b) once a fortnight | (e) any other |
| (c) twice a month | |

6. Have you ever received training in relation to the work you are doing?

- (a) yes
(b) no

7. If yes, do you find the training given to you to be of great help?

- (a) yes
(b) no

7.(a) If yes, explain how it is helpful to you. _____

8. Do you communicate freely with the CHBC team?

- (a) yes
(b) no

8. (a) give reasons for the above answer

9. What kind of counseling do you get from the team?

10. What kind of support do you get from various groups?

11. How many patients are under your care?

12. What is your patient suffering from?

13. How do you relate to the patient?

- | | | |
|------------|--------------|---------|
| (a) Mother | (e) daughter | (I) any |
| other | <hr/> | |
| (b) father | (f) son | |
| (c) aunt | (g) wife | |
| (d) uncle | (h) husband | |

14. Do you care for the patient willingly or you are forced to?

- (a) Willingly (d) any other

- (b) forced
- (c) no response

15. What problems do you encounter in relation to being a caregiver ?

- | | |
|---|---------------------------------------|
| (a) psychological problems | (d) lack of support from community |
| (b) lack of finance | (e) lack of knowledge on patient care |
| (c) lack of transport to take patient to clinic | (f) any other |

16. What do you think are the most needs of patients?

17. Any other relevant information ?

QUESTIONNAIRE FOR PATIENTS

1. Do you prefer to be taken care of at home or hospital?

- (a) at home (c) no response
(b) at the hospital (d) any other _____

2. Account for the above given answer. _____

3. What are you suffering from? _____

4. What kind of services are provided by the CHBC team ?

- (a) Medical (d) spiritual support
(b) Counseling (e) all of the above
(c) material needs (f) any other _____

5. How can you rank services given by the team?

- (a) very good (d) very poor
(b) good (e) poor
(c) fair (f) any other _____

6. Are you happy with the services that are given ?

- (a) yes
(b) no

7. (a) If no, what can be done to improve services to meet your needs ?

8. Do you think you can do without these services ?

- (a) yes
(b) no

9. What kind of services are needed most in your case?

10. Are you happy with the care-takers' services ?

- (a) yes
- (b) no

11. (a) If no , what are your suggestions towards improvement of the care-takers' care ?

12. Any other relevant information ?

QUESTIONNAIRE FOR POLICY MAKERS

N/B If for any reason you do not want to answer any of the questions below, please feel free to do so. Remember, however, that the study aims at helping to improve the Community-Home Based Care programme. Which we can only do if you provide us with accurate information. All information provided will be treated as strictly confidential.

SECTION A: BIODATA

1. SEX:
2. AGE (IN YEARS):
3. MARITAL STATUS
4. EDUCATION:
5. RELIGION:

SECTION B: POLICY MAKERS

Why do you think Community Home Based Care is the best way of caring for the HIV/AIDS patients?

Explain _____

2. What services do you have for the HIV/AIDS patients?

- (a) medical (c) transport (e) all of the above
(b) personnel (d) counseling (f) any other explain

3. How do you rate services provided to HIV/AIDS patients?

- (a) very good (c) fair (e) very poor
(b) good (d) poor (f) any other explain

4. What monitoring and evaluation mechanisms do you have on Community Home Based Care?

- (a) Workshops (c) reports (e) home visits
(b) seminars (d) education (f) any other

5. What problems have you identified about the CHBC programme?

- (a) shortage of personnel
- (b) shortage of transport
- (c) lack of funds
- (d) ignorance of caregivers on how to care for the patients.
- (e) all of the above

6. How do you think the system can be improved?

7. How is the system affecting your budget?

- (a) very much
- (b) much
- (c) badly
- (d) very bad
- (e) any other explain _____

8. Do you have adequate personnel to handle the situation?

- (a) yes
- (b) no

9a. If no, how do you hope to address the situation?

10. Is there any coordination of efforts in place to manage CHBC services to avoid duplication of services?

- (a) yes
- (c) no

10 (a) If no, how do you coordinate CHBC services?

- (a) through government staff
- (b) parastatal staff
- (c) CHBCteam
- (d) all of the above
- (e) any other explain _____

11. What strategies are in place to impart information on CHBC?

- (a) Workshops
 - (b) Seminars
 - (c) mass media
 - (d) educational campaign
 - (e) any other
-

12. Are the strategies effective?

- (a) yes
- (b) no

12. (a) If no, how do you intend to improve the strategies?

13. With the likely increase in HIV/AIDS patients in the future, what do you take to be the likely problems?

(a) shortage of staff

(d) any other _____

(b) budget constraints

©shortage of logistics

14. Any other relevant information _____

THANK YOU VERY MUCH FOR YOUR COOPERATION

QUESTIONNAIRE

COMMUNITY HOME BASED CARE (CHBC) TEAM

1. How many patients are under your care? _____

2. How often do you visit them? _____

3. What services do you render to care-givers?

- | | |
|-------------------------|----------------------|
| (a) information on CHBC | (d) all of the above |
| (b) protective clothing | (e) any |
| other _____ | |
| © counseling on CHBC | |

4. What services do you render to patients?

- | | |
|----------------------------|---------------------|
| (a) counseling on HIV/AIDS | (d) medical needs |
| (b) material needs | (e) social needs |
| (c) psychological needs | (f) spiritual needs |
| (g) any other explain | |
- _____

5. How can you rate services given to HIV/AIDS patients?

- | | |
|---------------|---------------|
| (a) very good | (d) very poor |
| (b) good | (e) poor |
| © fair | (f) any other |
- _____

6. How do you rate the relationship between you and patients?

- | | |
|---------------|---------------|
| (a) very good | (d) very poor |
| (b) good | (e) poor |
| © fair | (f) any |
- other _____

7. What problems do you normally encounter in your discharge of services?

- | | |
|-------------------------------|------------------------------|
| (a) shortage of logistics | (d) patients not cooperative |
| (b) shortage of transport | (e) any |
| other _____ | |
| (c) CHBC team not cooperative | |

8. How do you normally address these problems? _____

9. Do you consider CHBC the best system for caring for the HIV/AIDS patients?

(a) yes

(b) no

9.(a) if yes

explain _____

9.(b) If no, what any other system do you think can replace CHBC?

10. Do you have feed back mechanisms from care-givers and vice-versa?

(a) yes

(b) no

11. If yes, how is this carried out?

(a) through workshops

(d) home visits

(b) through seminars

(e) any

other _____

(c) monthly reports

12. What kind of training is offered to care-givers?

(a) given information on how to care for patients medication

(d) giving patients

(b) given skills on how to bath patients

(e) all of the above

© given skills on how to feed patients

(f) any

other _____

13. What strategies do you employ to impart information on CHBC?

(a) Workshops

(d) all of the above

(b) Seminars

(e) any other

(c) mass media

14. Any other relevant information.