

**THE PERCEPTIONS OF PEOPLE LIVING WITH HIV AND AIDS
ON COMMUNITY HOME BASED CARE**

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**A Research Project Paper submitted in partial fulfillment for the degree
of Master of Arts in the Department of Sociology, University of Nairobi**

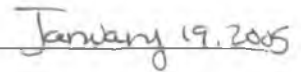
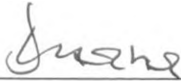
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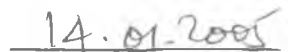
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Date

This Research Project Paper has been submitted for examination with my approval as University Supervisor.



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Date

TABLE OF CONTENTS

	Page
List of Abbreviations	(i)
Acknowledgements	(ii)
Dedication	(iii)
Abstract	(iv)

CHAPTER ONE

INTRODUCTION AND STATEMENT OF THE PROBLEM

1.1	Introduction.....	1
1.2	Problem Statement	2
1.3	Study Objectives.....	3
1.4	Justification of the study.....	4
1.5	Scope and limitations.....	5

CHAPTER TWO

LITERATURE REVIEW

2.0	Introduction.....	6
2.1.1	National level HIV/AIDS and health situational analysis.....	6
2.1.2	Effect of HIV/AIDS on health care.....	8
2.1.3	Community Home Based Care.....	9
2.1.4	PLWHAs' involvement in CHBC.....	11
2.1.5	Benefits of CHBC.....	12
2.1.6	Challenges of CHBC.....	13
2.1.7	Community Home Based Care in Kenya.....	14
2.2	Research gaps.....	15
2.3	Theoretical framework.....	16
2.4	Operationalisation of key terms and concepts.....	20
2.5	Research propositions.....	21

CHAPTER THREE

RESEARCH METHODOLOGY

3.1	Sources of data.....	23
3.2	Site of study.....	24
3.3	Sample selection and sample size.....	24
3.4	Unit of analysis.....	25
3.5	Data collection.....	25

3.4.1	Face to face interviews.....	25
3.5.2	Key informant interviews.....	26
3.5.3	Direct observation.....	27
3.5.4	Review of documentary material.....	27
3.6	Problems encountered in the field.....	27
3.7	Ethical considerations.....	28

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

4.1	Demographic variables of respondents.....	30
4.1.1	Sex of PLWHAs.....	30
4.1.2	Age of PLWHAs.....	31
4.1.3	Number of children.....	32
4.1.4	Education and employment.....	33
4.1.5	Marital status.....	34
4.1.6	PLWHAs' health.....	36
4.2	Analysis by Objectives.....	38
4.2.1	PLWHAs' knowledge and perceptions of the role of CHBC in the Provision of their care.....	38
	a) PLWHA knowledge of CHBC.....	39
	b) PLWHAs' sources of knowledge on CHBC.....	39
	c) PLWHAs' perceptions of the role of CHBC.....	40
4.2.2	Level of involvement of PLWHAs in CHBC.....	42
4.2.3	Priority needs which PLWHAs perceive as key for CHBC Interventions.....	45
4.2.4	Challenges and experiences of PLWHAs in CHBC.....	47

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS52

5.1	Conclusion.....	52
5.2	Recommendations.....	53

TABLE CONTENTS

TABLE NO.	CONTENTS	PAGE
1:	Sex of respondents	30
2.:	Age of respondents	31
3:	Number of living children/children living with respondent	32
4:	PLWHAs' source of income	33
5:	Illnesses commonly suffered by PLWHAs	37
6:	PLWHAs' knowledge of CHBC issues	38
7:	Sources of information of CHBC	39
8:	Role CHBC plays in the lives of PLWHAs	40
9:	What PLWHAs do to take care of themselves	43
10:	Things PLWHAs are not able to do for themselves	44
11:	People who involve PLWHAs in CHBC	44
12:	Desirable ways for greater involvement of PLWHAs	45
13:	Important needs vs available needs	46
14:	Challenges faced in CHBC	48
15:	How PLWHAs tried to overcome challenges in CHBC	50
Figures:		
1:	Marital status of respondents	35
2:	Religious affiliation of respondents	36
3:	Need importance vs. need availability	47

LIST OF ABBREVIATIONS

AIDS -	Acquired Immuno-deficiency Syndrome
CBD -	Community Based Distributor
CBO -	Community Based Organization
CHBC -	Community Home Based Care
CHW -	Community Health Worker
DCT -	Diagnostic Counseling and Testing
DFID -	Department for International Development
GIPA -	Greater Involvement of People Living with HIV/AIDS
GoK -	Government of Kenya
HAPAC -	HIV/AIDS Prevention and Care Project
HBC -	Home Based Care
HIV -	Human Immuno-deficiency Syndrome
KHADREP-	Kenya HIV/AIDS Disaster Response Program
KNASP -	Kenya National AIDS Strategic Plan
KNHSSP -	Kenya National Health Sector Strategic Plan
MOH -	Ministry of Health
NACC -	National AIDS Control Council
NASCOP -	National AIDS/STI Control Program
NGO -	Non-Governmental Organization
OVC -	Orphans and Vulnerable Children
PEPFAR -	President's Emergency Plan for AIDS Relief
PLWHA -	People Living with HIV/AIDS
PMCT -	Prevention of Mother to Child Transmission
QOL -	Quality of Life
UNAIDS-	United Nations Joint Program on AIDS
UNICEF -	United Nations Children's Fund
VCT -	Voluntary Counseling and Testing
WHO -	World Health Organization

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DEDICATION

This Research Project Paper is dedicated to my children Tindi, Samba and Wendo:
recognizing that *it isn't where you come from, It's where you are going that counts!*
May the pursuit of higher education be your constant endeavor.

ABSTRACT

The perceptions of PLWHAs on CHBC may be as important to understand as would be the practical delivery of services targeted at them. There has been a reduction on HIV prevalence, but the management of HIV/AIDS even when ARVs are available continues to present a major challenge to PLWHAs. In Kenya, implementation of CHBC has been widely supported, and national efforts have resulted in the development of policies, guidelines and manuals to guide this effort. However, it is still unclear how the beneficiaries of CHBC perceive this form of care. There have been no studies in Kenya to document the perceptions and experiences of PLWHAs with CHBC. It is against this background that this study was launched.

This study aimed at investigating the perceptions and experiences of PLWHAs with CHBC as well as their actual involvement in CHBC activities. The specific objectives are as follows:

- Examine the PLWHAs' knowledge and perception of the role of CHBC in provision of their care
- Assess the level of involvement of PLWHAs in CHBC
- Identify priority needs that PLWHAs perceive as key for CHBC interventions
- Investigate and establish the experiences of PLWHAs with CHBC

Quantitative data for this study was collected from a purposively selected sample of seventy respondents in four villages of Kangemi informal settlement in Nairobi. Augmentative qualitative data was also collected from in-depth interviews with ten key informants who were also community health workers serving as caregivers for PLWHAs. Supplementary data were also obtained through the field observations.

The findings of this study suggest that PLWHAs have sufficient knowledge about CHBC and this knowledge guides their perceptions of CHBC. PLWHAs need to be involved to a greater extent in HIV/AIDS issues, particularly to help them acquire a wider understanding about HIV treatment and the avoidance of opportunistic infections.

PLWHAs identified clinical, nursing, counseling/spiritual, social support and other material needs as essential in their care. While needs appeared to vary considerably, most of the needs identified were largely associated with resource deprivation.

Key challenges included limitations in accessing nutritional support, lack of material resources such as shelter, limited access to clinical care and referrals and stigma. Nutrition was considered as the greatest challenge that adversely affects the attainment of CHBC goals.

Based on the findings of this study, there is need for greater participation of PLWHAs in more aspects of CHBC. The need to support an increased participation of PLWHAs in facilitating their own care at home is highly encouraged.

CHBC should be multi-faceted programs in order to provide linkages to other aspects of care and support of PLWHAs. Counseling and community education should also be extended to the PLWHA's family members and the wider community in order to reduce the social stigma associated with HIV/AIDS as well as to increase the acceptance of CHBC so as to improve the quality of life for PLWHAs.

CHAPTER ONE

INTRODUCTION AND STATEMENT OF THE PROBLEM

1.1 INTRODUCTION:

There is an increasing urgency to address Care and Support of people infected and affected by HIV and AIDS in Kenya. This is so given the rise in HIV incidence and prevalence. Current prevention efforts are aimed at decreasing the incidence of new HIV infections, yet even where prevalence is indeed reported to be stabilizing, the need for Care and Support then assumes a priority focus. This is so because for the already infected, the progression of HIV immuno-suppression (owing to limited access to health care and other socio-economic constraints) promotes the rapid advancement of the disease. In essence, this calls for Care and Support of the affected and infected, to facilitate an improved quality life.

One of the National AIDS Control Council's (NACC) goals is to reduce HIV prevalence by at least 20% among people aged 15 – 24 years by the year 2005 (KNASP, 2000). However, Gilks (1988) argues that while efforts to achieve this target are underway, the already-infected population will be recording an increased demand for access to Care and Support services as their HIV infection progresses to AIDS.

One of the priority areas and strategies of the Government of Kenya in its National HIV/AIDS Strategic Plan (KNASP) 2000 - 2005 is among others, the 'treatment and support of continuum of care of the infected and affected' (KNASP, 2000). The overarching goal of this priority strategy is the improvement of the Quality of Life (QOL) for People living with HIV/AIDS, which subsequently helps both the infected and affected to better cope with their HIV status. At the forefront of efforts that have demonstrated an active involvement in the fight against HIV/AIDS are varied interventions spearheaded by Non-Governmental Organizations (NGOs) and Community Based Organizations (CBOs)

Three key documents guide policy and the implementation framework for the provision of CHBC in Kenya: the National Home Based Care (HBC) Policy Guidelines (2002), National HBC Programme and Service Guidelines (MOH, 2002) and the Home-Based Care handbook (MOH, 2002). These spell out the Government of Kenya's (GoK) official basic components of home care services, programmatic standards and the requirements for service delivery. These have set out the centrality of involving PLWHAs in the provision of services, including care that supplements formal health care.

1.2 PROBLEM STATEMENT

Relative to other HIV prevention and treatment efforts, Care and Support for PLWHAs within their home and community environment is a relatively new response in the arena of this epidemic. This care entails the involvement of family and community members taking care of their sick at home as an alternative to formal, hospital-based health care. This care is hereafter referred to as Community Home Based Care (CHBC). Away from the family, various other community members comprise the next level in the provision of Care and Support services for those infected and affected. Various interventions have sought to involve a range of community members e.g. community health workers, health care workers and caregivers in an effort to provide Care and Support to People Living with HIV/AIDS (PLWHAs) and their affected ones.

This far however, there are anecdotal reports of varied experiences and challenges that stand in the way of provision of home-based care within community settings. Considerably little progress has been made, particularly by families in this aspect and there is a current neglect of the care agenda as Gilks emphasizes in DFID's Strategy Paper (1988).

In consideration of the investment and efforts by the Ministry of Health, community and Non-governmental organizations that have gone into setting up and planning for implementation of CHBC programs nationwide, PLHA perceptions are worth understanding so that future community Care and Support programs are intelligently guided in their replication and scale up. These initiatives should essentially ensure that they are responsive to PLWHAs felt needs. Central to the efforts to provide this care to

PLWHAs, is the individual involvement of PLWHAs in contributing to their own healthcare. To help us ensure that along care and support spectrum, the vast forms of CHBC roles by key players are actually in tune with and reflect what the PLWHAs consider as a contribution to their state of well-being, a good understanding of the perceptions of PLWHAs regarding the CHBC service they receive is paramount. There is need for an in-depth understanding of the actual beneficiary perception of what this CHBC means to their well being. It is also important to find out what the PLWHAs feel about the efforts that are being invested for their own good. Hence, there is need to investigate into the feelings and attitudes of PLWHAs towards CHBC.

In its attempt to investigate the actual perception of PLWHAs regarding the role of CHBC in improving their well being, this study is guided by the following questions:

- (i) What is the PLWHAs' knowledge and perception of the role of CHBC in provision of their care?
- (ii) How do PLWHAs become involved in CHBC and what is their level of participation in these programs?
- (iii) What do PLWHAs identify as their priority needs and to which CHBC should therefore respond?
- (iv) What are the experiences of PLWHAs with CHBC?

1.3 STUDY OBJECTIVES

The overall objective of this proposed study is to examine and document the PLWHAs' perception of the CHBC services that are aimed at improving their wellbeing. The proposed study will focus on the following objectives:

1. To examine the PLWHAs' knowledge and perception of the role of CHBC in provision of their care.
2. To assess the level of involvement of PLWHAs in CHBC.
3. To identify priority needs which PLWHAs perceive as key for CHBC interventions.
4. To investigate and establish experiences of PLWHAs with CHBC.

1.4 JUSTIFICATION OF THE STUDY

Some of the Kenya Ministry of Health's objectives in the Reform and Restructuring of the Ministry of Health include 'involving the various stakeholders in program design, planning and implementation' (KNHSSP, 1999). The centrality of activating community participation is therefore predominant in health programmes, including HIV/AIDS programs.

This involvement of a wide range of players has been enlisted to help beef up efforts of an overwhelmed formal health care system by indulging in collaborative efforts with health care facilities and families in caring for their sick and affected within their own homes through family and community involvement (KNASP 2000). Although care for ill persons within families and communities has existed through traditional social systems, the challenge that HIV/AIDS brings to light is the need to improve the Quality of Life of PLWHAs through offering them dedicated care and support within their home setting, hence the significance of CHBC.

Care and Support programs are not only expensive but they also take up a lot of family and community effort. They are also constrained by other evident factors, particularly stigma. An important consideration in stigma reduction is ensuring a Greater Participation of People Living with HIV/AIDS (GIPA) which is a principle that was adopted by governments at the 1994 Paris AIDS summit. The principle advocates for an increased involvement of PLWHAs in decision making, planning and implementation of efforts targeted to benefit them. This spells the need to delve into investigations that centrally involve the PLWHAs in outlining their perceptions of the CHBC that are designed to provide them with better care.

Efforts are continually being made to roll out an implementation of varied Care and Support initiatives to combat the AIDS pandemic among affected populations. In Kenya, the World Bank funded Kenya HIV/AIDS Disaster Response Programme (KHADREP) and the United States' President's Emergency Plan for AIDS Relief (PEPFAR) have for

example set aside substantial amounts of funding to facilitate increased care and support for PLWHAs. This spells the need to focus on the essential elements that enhance HIV/AIDS Care and support.

This far, there is little documented evidence to show whether the guidelines and indicators developed to ensure improved Quality of Care in CHBC do in fact provide flexibility for incorporation of PLWHAs felt needs to enrich programs. Additionally, it is important to assess whether efforts such as CHBC relate to what their target beneficiaries perceive as their needs. In consideration of both the amount of investment that has been set aside for HIV care and support as well as the increasing need to offer care and support for the infected population, this study is of significant knowledge value. Moreover, its findings are an invaluable body of knowledge in guiding the planning of CHBC programmes so that they become continually enriched to deliver better outputs. A study of its kind will also provide information to fill existing academic gaps.

1.5 SCOPE AND LIMITATIONS

The focus of this study was on Community Home Based Care for People Living with HIV/AIDS. The main emphasis of the study was to assess the PLWHAs' perceptions of CHBC in relation to the improvement of their well-being. This study was therefore limited to PLWHAs who already had some active involvement as players or recipients in the provision of CHBC, mainly through existing initiatives for at least six months. This was to help ensure that their perceptions reflected actual experiences gained over time. The study also sought to relate challenges in the provision of CHBC to priorities that PLWHAs identified as key for their improved well-being. While there are many actors involved in the provision of CHBC, this study was limited to assessing the perceptions of the ultimate beneficiary: the PLWHA.

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

The purpose of this literature review was to make clear the theoretical context of the problem under investigation and demonstrate how it has been studied by others as well as identify research gaps.

2.1.1 National Level HIV/AIDS and Health Situational Analysis

Kenya is committed to the WHO prescribed Primary Health Care (PHC) Strategy, WHO (1988). In the Kenya National Development Plan (1989-1993), it states in part that 'Kenya subscribes to the principles contained in the Alma-Ata declaration of 1978, which stresses the need for any meaningful strategies in developing countries to introduce approaches for the provision of essential health services that correspond to basic needs, are universally accessible and allow for the full participation of the communities themselves'.

Notable efforts have been seen in Kenya whilst trying to operationalize this vision through the development of Primary Health Care (PHC) initiatives in varied parts of the country. For example, a MOH/UNICEF study seeking to address the need for a PHC strategy saw participants singling out the role of a Community Health Worker (CHW) as 'a resident health care provider and advisor with promotive and disease preventive roles, in addition to curative and first aid services roles'. This aspect may be seen as an early recognition of the significance of promoting health at community level, away from the mainstream health-facility service providers and most importantly, encouraging community members to play an active role in health promotion.

Consistent with the Alma-Ata/PHC commitment, more recent policy objectives contained in the Kenya National Health Sector Strategic Plan (KNHSSP) 1999-2004 provide direction in ensuring coverage of communities in health care provision. It states in part

that: ‘...the country will reduce the burden of disease resulting from vaccine-preventable diseases, HIV/AIDS, Malaria and other diseases by the end of the year 2004; expand the coverage and accessibility of health services for the underserved rural communities in a phased approach during the next five years...and encourage and financially support community and non-governmental initiatives in provision of health care in the districts.’ (KNHSSP, 1999).

This commitment has however been punctuated by various daunting challenges that have hampered the journey to providing increased disease prevention and access to health services. Key among these challenges has been HIV/AIDS, which is the leading cause of disease and death in Kenya and Sub-Saharan countries (UNAIDS, 2002).

To respond to the HIV/AIDS challenge, the KNASP 2000-2005 provides a policy framework within which NACC manages its national responsibility to mobilize resources, strengthen policy, plan and co-ordinate the multi-sectoral responses to HIV/AIDS in Kenya. The KNASP, has its strategy achievement pegged along five priority areas namely:

1. Prevention and advocacy
2. Treatment, continuum of care & support
3. Mitigation of the socio-economic impact
4. Monitoring, evaluation and research
5. Management and co-ordination

Underlying the Continuum of Care and Support strategy are efforts co-ordinated by the MOH's NASCOP to strengthen the involvement of various players in CHBC. The PLWHAs are essentially included as key players in the CHBC field.

The KNASP framework that was developed within the context of the declaration of a HIV/AIDS disaster situation in Kenya in the late 1999. This by implication rendered operations under it of a somewhat emergency nature. Only four years after the declaration of the HIV/AIDS disaster situation in-country, Kenya's world-ranking continues to be

evidently alarming on the global map. Kenya is now reported to have the fourth highest number of HIV-infected cases of any country of the world. Moreover, it is ranked the 7th highest country to have the highest proportion of its population infected (UNAIDS, 2002).

This Kenyan situation is consistent with the global devastating picture, which assigns three quarters of the world's HIV- positive people as living in Africa (UNAIDS, 2001). However, in-country, the National Sentinel surveillance reports record a more encouraging picture. As at 2002, Sentinel Surveillance had recorded a national level decrease to a 10.2% infection rate, down from 13% in 2002. (NASCOP, 2003). The 2003 Kenya Demographic and Health Survey (KDHS) results recorded a 6.8% prevalence while the Sentinel Surveillance rate was 9.4%. This decrease is attributable in part to the early prevention interventions. However, one of the effects of this epidemic is the reported drop in life expectancy from 65 (in an absolutely low HIV prevalence scenario) in 1991 to 46 years presently, and will be 45 years by 2010. This analysis by the Kenya Central bureau of statistics provides evidence for a gross loss of nearly 20 years of life to an ordinary life. The estimated daily loss of lives arising from AIDS is 700 persons. New infections per year are estimated at over 200,000 while the cumulative number of those already dead is 1.5 million. 2.2 million are living with HIV/AIDS, with at least 10% of these being in the 15-49 age bracket (NASCOP, 2001).

2.1.2 Effect of HIV/AIDS on Health Care:

One of the adverse sectoral impacts that HIV/AIDS has made is an increased burden on the health sector. The challenge of caring for those infected with HIV/AIDS has overstretched the health sector's capacity to meet the country's health needs. NASCOP (2001) recorded increased costs on health care, with a total cost per AIDS patient amounting to Kshs. 573,240.00 (estimated Kshs. 34,680 in direct treatment costs and Kshs. 538,560 in total indirect costs).

A more vivid illustration of the visible effect of HIV/AIDS on health care is the drastic increase in hospital bed occupancy, now standing at 51% for AIDS-related illnesses.

This upward surge on the demands on hospitals constrains health care facilities and consequently undermines their capacity to respond to other critical health needs e.g. malaria and under-five morbidity.

With more than 2.2million people in Kenya infected with HIV today, it is imperative that appropriate modes of treatment and care are sought and that they be available, accessible and appropriate for people living with HIV infection and AIDS disease as well as their families. Away from governments, the basic family unit and the community are perhaps the most important and most realistic units to share responsibilities in handling the consequences of HIV/AIDS by having to care for their own unwell. Households are recognised as key units in health care delivery. This therefore sets the stage for CHBC.

2.1.3 Community Home Based Care (CHBC)

The WHO defines CHBC as any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities (WHO,1993).

The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life. This helps to rest the health care responsibility of care with the families of (usually chronically) ill people, including PLWHAs. The participation of families and additionally, communities in CHBC is further reiterated by the NASCOP's description of CHBC, which unlike WHO confines the practice to the HIV/AIDS situation. It describes CHBC as the care of persons infected and affected by HIV/AIDS that is extended from the hospital or the health facility to their homes through family participation and community involvement within the available resources and in collaboration with health care workers (MOH/NASCOP, 2001). This strategy advocates for the active participation and involvement of those most affected – the persons living with HIV/AIDS (MOH/NASCOP, 2002).

An integral aspect of responses to HIV/AIDS is the participation and collaboration of all sectors of society, which should then see the private sector, NGOs donors, communities,

religious communities and educational institutions all join up their efforts against AIDS (MOH, 1997).

The WHO policy framework has provided essential systematic parameters to guide policy makers and implementers in both designing and implementing their programs. This framework is therefore an essential point of reference in reviewing CHBC practices both in this study as well in implementation practice. The essential elements and scope of CHBC as contained in the WHO framework include the following:

1. Provision of care: this entails providing not just individual services but comprehensive care to people living with HIV/AIDS
2. Continuum of care: this ought to be linked with a referral system, spanning home to hospital and should ideally involve integrating the model of care into the government health care system
3. Education: Including a prevention component for both the PLWHAs, caregivers and community.
4. Supplies and equipment: availing essential items to facilitate home-care.
5. Staffing: Facilitating close co-ordination and cooperation between NGOs, government health services and communities
6. Financing and sustainability: Utilizing the existing community resources with sustainable support mechanisms
7. Monitoring and evaluation: keeping track of inputs and outcomes of CHBC for systems improvement.

Any reviews on CHBC should therefore use the above guides as primary goalposts in assessing programme implementation. Additionally, WHO has outlined a quality assurance framework for enabling an effective CHBC. This framework includes developing the standards, policies, goals, objectives and practice guidelines for regulation of CHBC, which Kenya has already accomplished. In these guidelines, the roles and responsibilities of CHBC team members have been spelt out, so have the requisite resources staff, supplies, equipment and education for CHBC.

The components of CHBC as stipulated in the Kenya HBC policy guidelines include clinical care, nursing care, counseling/psycho-spiritual care and social support. It is within this broad framework that community involvement is expected. Within the home, it is expected that medical care be continued. Similarly, the PLHWAS should be assisted to alleviate physical and psychological symptoms through nursing care. The reduction of anxiety and the promotion of positive living is aided through counseling and psycho-spiritual support and this particularly works as an advocacy for behaviour change and stigma reduction, both for the PLHwAs as well as family and community members. There are broader needs outside of the family that require social support from the larger community, for example the provision of material things, the protection of children affected by HIV/AIDS, support groups for PLHA and legal services.

2.1.4 PLWHAs Involvement in CHBC

Consistent with the GIPA principle mentioned above, the meaningful participation of PLWHAs in both programme and policy formulation and implementation is crucial to ensure success of initiatives targeted at and involving these beneficiaries. Within the WHO scope of CHBC are essential elements that encourage the PLWHA involvement in the provision of their care. These include educating the ill person on provision of care to enhance their understanding of the care benefits and their role. It is also important to ensure access to free and affordable Health Care, which is perhaps the most challenging element in Kenya. Transport and access to essential drugs and supplies is very important in the provision of care. A particularly significant need is the availability of adequate symptom relief for pain or other infections. The use of universal precautions against infections is recommended for the PLWHAs. An adequate nutrition plays as great a role as does medication and ought to be ensured. Other necessities include basic nursing care and comfort measures e.g. cleanliness of the ill person, general house cleanliness, adequate clothes and bedding, mobility of the ill person where appropriate and adequate heat and ventilation. Away from the physical needs, psychosocial support and counseling, including voluntary counseling and testing, promoting shared confidentiality and reducing the family and community stigma associated with illness and care are all of significant importance. Owing to the complexity of HIV related disease, adequate

referral and access to community resources is essential to complement home-care. Overall, the need for PLHA's satisfaction with Quality of Care, which indeed ought to improve the ill persons quality of life is of importance, hence the need for this study.

Despite the challenges that would confront such an ideal health care delivery at home, an estimated 70% of illness care takes place within the home (WHO, 2000). The very persons who are involved in providing this primary care therefore ought to both understand their role as well as participate in decision making processes, implementation, sharing benefits and evaluating programs. This would ideally lead to an improvement of mechanisms through which such care is provided, in the quest for achievement of healthcare goals.

2.1.5 Benefits of CHBC

Various research studies have reported that the home offers the most ideal environment for the care of its family members and that sick ones actually prefer to be cared for at home. As opposed to hospital-based care, home care provides increased social support from family and friends and this should ultimately contribute to an improved state of well being, not only for the patient but also for other family members. Armstrong (1983) stipulates valid arguments for community and home care which he sees as an ideal alternative to the formal health care system, and argues that these must be sustained except in cases where the illness is too difficult and too serious to be managed within the home. He advances merits that are consistent with lessons learned from experiential evidence drawn from various HBC initiatives in Africa and Asia.

Terminally ill people generally prefer to stay at home, especially when they understand the terminal nature of their illness. Sick people often feel more comfortable receiving care in their own family homes and living with their communities close to them. In the context of an epidemic such as HIV/AIDS, CHBC decongests hospitals in the wake of a marked increase in bed occupancy. The capacity of Kenyan hospitals to provide care is dwindling with reduced expenditure on health. This decongestion should ultimately contribute to improved service provision by hospitals. Arguably, CHBC is less

expensive. Though varied cost-effectiveness studies are still underway, home care is more affordable than hospital care as families are able to provide care within their available means. Armstrong (1983) however believes there are major 'hidden additional costs' which may leave the family more heavily burdened than if indeed the formal health care system took up its requisite government expenditure on health care. In view of this burden of responsibility, care can be shared out amongst various family members and friends in CHBC, hence reducing the workload and freeing up people to reasonably handle their daily chores simultaneously.

Perhaps a most important benefit of CHBC is its facilitation of the GIPA principle given that the involvement of PLWHAs is recommended as it strengthens their capacity to contribute to their own improved quality of care. In the face of HIV/AIDS stigma and discrimination, CHBC puts a human face to both the PLWHAs and affected ones as well as to home-care. A key player identified in the spectrum of CHBC is the PLWHA, whose roles could include identification of their caregivers, participating in the care process in as far as he is able to and taking a personal responsibility to protect others from HIV infection through positive living.

2.1.6 Challenges of CHBC:

Along with the evident benefits of CHBC are arguments against it, which are important in understanding the validity of this concept, as well as in integrating them to programme planning and review. One of the potential problems of healthcare is the disintegrating family unit, hence sick people continually find themselves without the ideal 'family unit' available to take care of them. An associated difficulty is the changing role of women from traditional caregivers to career women, hence a glaring gap in reliable care provision. Additionally, Armstrong (1983) cautions against the limited lack of ample knowledge about CHBC costs and benefits, hence it should not be taken for granted as being the ideal wholesome.

An identification of mechanisms which could contribute to the success or failure of CHBC systems has been highlighted by Limanonda, (2001). These include the

willingness of PLWHAs and families to reveal themselves owing to stigma, hence they would neither allow CHBC service providers to reach them, nor would they be open to practicing it. Owing to this stigma therefore, acceptance and understanding of the PLWHA, alongside the community and family about the benefits of CHBC is limited, especially in instances where there is a lack of well-equipped organizations e.g. NGOs, CBOs, FBOs. Given the magnitude of the epidemic, meaningful coverage would be best achieved in the presence of a sound acceptance by PLWHAs as the ultimate beneficiaries. Efforts to reach communities with CHBC are often subdued by resource constraints among others, owing to increasing numbers of infected and AIDS patients and subsequent increase in demand for services. An overriding issue is indeed the challenge to link delivery of Quality of Care in CHBC with beneficiary perceptions of their needs.

2.1.7 CHBC in Kenya

As early in the epidemic as 1993, the MOH, Kenya set out national guidelines on CHBC, which primarily emphasized on its focus being to ensure a ‘ **Provision of quality care**, an appropriate response in dealing with limited resources, minimizing health worker load and providing for a continuity of care following discharge from hospital’.

More recent guidelines by the MOH/NASCOP (2002) have provided a closer focus on HBC objectives as spelt out below:

- a) To facilitate the continuity of the patient’s care from the health facility to the home and community
- b) To promote family and community awareness of HIV/AIDS prevention and care
- c) To empower PLWHAs, the family and the community with the knowledge needed to ensure long-term care and support.
- d) To raise the acceptability of PLWHAs by the family/community, hence reducing the stigma associated with AIDS.
- e) To streamline the patient/client referral from the institutions into the community and from the community to appropriate health and social facilities.
- f) To facilitate quality community care for the infected and affected persons.

g) To mobilize the resources necessary for sustainability of the service.

It is therefore important that implementers of CHBC understand the parameters within which they ought to provide CHBC. Most importantly, it is crucial that as stated in ('c') above, the PLWHA is both informed as well as actively involved in ensuring the long-term Care and Support Quality of Care.

2.2 Research Gaps

In key policy and strategic documents guiding the practice of communities as well as that of the health sector and which have been reviewed in this study e.g. KHSSP, NASCOP HBC guidelines, MOH/NASCOP Home Care Handbook, KNASP, WHO Action Research for CHBC in Kenya, CHBC is unanimously recognized as an important aspect in the implementation of successful health care initiatives through improving Quality of Care. What however is lacking is an in-depth understanding of the PLWHA's own perceptions regarding the CHBC as aimed at improving the care they receive and so that the said services appropriately respond to PLWHA needs. That CHBC is still at an infancy stage in Kenya's response to the epidemic is however acknowledged. However, as individuals, organizations and the national co-ordinating bodies prepare to gather up the momentum of implementing policies and implementation guidelines, it is key to understand what the PLHA actually identifies as the contribution of CHBC in provision of Quality Care.

The existing literature therefore evidently leaves a knowledge and practice gap in linking the practicalities of perceived PLWHAs Quality of Care aspects to the initiatives by CHBC projects. Additionally, an understanding of the relevance of the key existing guidelines for CHBC in the country must be guided to ensure that they are providing an adequate response to the felt needs of PLWHAs for improved Quality of Care.

Because not much groundwork has been covered in the implementation of CHBC, it is essential that new knowledge be scientifically collated to serve as an essential guide to both upcoming and existing interventions.

Based on this literature review, it is evident that this study will add value by enlarging the current body of knowledge that will help link practical PLWHAs perceptions on provision of Quality of Care to planning for successful CHBC initiatives.

2.3 THEORETICAL FRAMEWORK

In the course of reviewing relevant literature, this section will proceed to present the underlying theoretical rationale for the research. This approach is consistent with scholarly practice on scientific research approaches, which requires that research be backed by theories. The guiding theories surrounding this study are the Functional Theory and the Sick Role Theory. The Functional theory is applied to the CHBC function, while the involvement of PLWHAs as the unit of analysis in the study is reviewed against the Sick Role Theory.

Functional theory can be traced from the early works of Auguste Comte (1798-1857), Herbert Spencer (1820-1903) and Emile Durkheim(1858-1917), and later refined by Talcott Parsons and Robert Merton. The underlying view of functionalist theory is that social order as a consensual agreement reflects shared values and norms that bind a community together. In relation to the roles of various players in CHBC and their involvement in informal health care, a common framework governing the practice of CHBC guides their involvement within given communities. CHBC is driven by the commitment of individual players in a community to participate in providing a reasonable well being to the infected and affected. CHBC moves beyond the individual PLHA and seeks to include the families and most importantly, the larger community set up so that a general state of social order can be sustained. There are therefore functional prerequisites that will serve as a foundation for a CHBC initiative to work in a mutual agreement so as to foster improved Quality of Care.

Farganis (1993) analyzes the reason why people obey rules of a society as being that they see existing structures as legitimate expressions of consensus. More importantly, rules and regulations are designed to benefit the totality rather than the expressions of a dominant class or particular interest with privileged access to decision-making power.

The essence of people's involvement in community health care ought always to be their understanding that CHBC is their responsibility and that it actually does benefit both themselves and their loved ones.

As discussed in the literature review, unlike hospital-based care, CHBC does not lead to a certain class of people wielding power but instead dissolves decision-making power to rest in the hands of several participants by involving a wider community involvement.

Away from its focus on the health care, the essence of CHBC is contextualized within a systems approach to strengthening the very practice of care and support for PLWHAs and their families. Furthermore, the importance of strengthening linkages with multiple sectors e.g. the Ministry of Health, Social support services, Faith Based organizations etc, provides vital pointers towards the need to conform to established systems.

Within the confines of Functionalism, this study will be guided by the contributions of Talcott Parsons (1902 – 1979) to functional social order. Parsons' fourfold classification scheme of the functional imperatives of a social system include Adaptation, Goal Attainment, Integration and Latency (commonly referred to as the AGIL principles).

The following section will proceed to relate each of these aspects to the study, as described by Fraganis (1993) and Giddens (1996).

Adaptation refers to the fact that systems are embedded in physical and socio-political environments to which they must adapt if they are to survive. The CHBC programs are ideally part of or linked to other health and development initiatives. In the Kenyan example, CHBC falls squarely under the mandate of the MOH, though multiple other players are drawn from a cross section of society to comprise the CHBC players. More importantly, it falls within the traditional African systems of caring for sick ones at home. The change-over of family systems e.g. in having career women or disintegrated family units within households as well as the escalating demands of AIDS disease however poses new challenges in caring for sick ones at home. These changes and influences of changing socio-political environments are as much an asset as they are a threat and

therefore, all stakeholders must employ adaptive mechanisms to the rapidly-changing environments, while responding to the emergency of the epidemic's care and support needs. An underlying issue here is the mobilization of resources, including the people themselves as an essential resource so that they harness all mechanisms around them to work in their favor.

CHBC requires a diverse resource mobilization to bring in key players e.g. health care facility staff, social services, spiritual support services and government departments.

Goal Attainment refers to the need in any system to define its primary goals and the methods by which individuals accept those goals as their own and strive to achieve them. The burden that HIV/AIDS places on the individual, the family and the immediate community members is beyond any reasonable doubt understood by the families as their own burden. They therefore understand the need to provide care and support for PLWHAs, as they would in other illnesses. However, at the center of all CHBC efforts, the PLWHA or other chronically ill person needs to be acknowledged as the ultimate beneficiary of these efforts. This is because as indicated in the literature review, the primacy of people should be an integral principle in the CHBC process so that their interests, needs and wishes are prime. This explains the essence of this study; to delve into an investigation that places the PLWHA at the center of all efforts targeted at improving the Quality of Care they receive.

Integration refers to the need to coordinate the component parts of the system so that they contribute to the maintenance of the whole. The roles of PLWHAs and all other CHBC team members are all embedded within the priorities of the KNASP. At the community level, CHBC takes place within a network of team members, which may include CHWs, health care personnel, counselors, behavior change specialists, families, team leaders etc. Diverse initiatives across an expansive geographical scope of CHBC interventions should serve to contribute to a set national programme goal e.g. improved quality of care for PLWHAs as contained in the NASCOP service guidelines. These ought to subsequently contribute to the attainment of KNASP's national goals. The coordination mechanism at the implementation level needs to be clearly coordinated amongst PLWHAs, family/non-

family caregivers, community members, GoK departments etc. More significantly, the input of various CHBC team members must ultimately ensure that the processes and activities both makes significant improvement to the quality of people's lives but also ends up with better programs.

Latency refers to those structures that serve to maintain and revitalize the motivation of individuals to perform their roles according to the social expectations. The underlying question here is 'what is the value added in introducing CHBC as a supplemental part of health care?' It is important therefore that this study makes a critical analysis of factors that would strengthen or impede an invigorated Quality of Care provision in CHBC. Underlying this understanding is the need to be sure that efforts actually result in the PLWHAs feeling that their quality of care has been indeed improved.

Even with the above idealistic approach to functional theory, it is recognized that one of the criticisms against Functionalism in Neo-functionalist approaches is that the former tends to be overly oriented towards the stability and equilibrium of large scale social systems. This thought is acknowledged in this study in the sense that it recognizes the underlying challenges that would hamper the delivery of Quality Care and subsequently, dampen CHBC efficacy. These inherent limitations in the course of operationalizing CHBC are indeed acknowledged rather than ignored by this study.

Another theory examined in this study is the Sick Role theory. In it, Parsons conferred certain expectations on the sick person which include the following:

- That the patient be temporarily excused from normal social roles for the period of their sickness until they return to normalcy.
- The sick person ought not to be held responsible for their illness but instead should be accorded all necessary support to facilitate recovery as he illness rendered the patient incapacitated.
- Owing to the 'removed' responsibility, significant responsibility is placed upon the family and other members responsible for one's welfare to obtain competent help to facilitate the sick person's recovery.

- The patient should recognize the ill state as undesirable and hence seek medical attention, exhibiting cooperation with those facilitating his/her path to recovery. Quite importantly, the cooperation of the patient with the doctor through adhering to treatment and other medical advice is crucial for their recovery.

This study generally refutes the inclinations presented in this theory. A major flaw in the Sick Role theory is that it overemphasizes the medical aspect of controlling patients' health care. The theory's arguments also tend to limit thinking towards patients with short-term illnesses. Additionally, it is limited to conceptualizing health care in a strictly institutional setting.

The study will seek to explain the significant role that both the PLWHA as a patient as well as the CHBC team members (who are largely non-medical) play in contributing to the well being of the patient. Unlike the Parsonian thinking which ignores the non-medical contribution to patients' well being, this study proposes to investigate a non-medicalized social approach to improving health care delivery. Whereas a PLWHA in the context of CHBC is not victimized or causing their illness, yet this care is confronted by eminent stigma and places a big responsibility on PLWHAs in the provision of Quality Care to ease their state of illness. Most importantly, it is the patient and other players in the CHBC team who take center stage in managing chronic HIV/AIDS illness.

2.4 OPERATIONALISATION OF KEY TERMS AND CONCEPTS

Key terms used in the study are clarified as follows:

CHBC: This will refer to any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities' as defined by WHO, (1993). Though the MOH/NASCOP definition tends to limit its definition to the care of PLWHAs and their families, its use in this study encompasses persons suffering from any chronic illnesses, including any unconfirmed HIV status. This is because the objectives of CHBC remain uniform irrespective of cause of illness and moreover, it helps in destigmatizing the function of CHBC. Moreover, unless VCT or other diagnostic testing

has been done, there would be no solid basis upon which to link any chronic illness to HIV disease. CHBC is a social support network put in place to beef up the more informal (traditional) networks. The collaborative efforts between hospital, family, community and the PLHA are essential for this approach to improve health care.

Participation / Involvement: These are used interchangeably to explain active processes by which players become involved in guiding the direction of their interventions with a view to strengthening its outcomes.

PLWHAs: People living with HIV or AIDS will include persons with confirmed or unconfirmed sero-status. In the context of CHBC, they would be people enlisted for involvement in interventions of Care and Support. Because of the likelihood of encountering persons with non-confirmed or undisclosed HIV status in the course of the study but who are participating in CHBC interventions, the study will be respectful of such confidentiality and hence consider such persons valid for inclusion as units of analysis.

Quality of Care:

This will refer to improved standards of taking care of PLWHAs in line with the parameters that guide the CHBC process. Most importantly, the operational definition in this study will be guided by the PLWHA perception of a better standard of care that is occasioned by CHBC and which overall contributes to a better quality of life.

2.5 PROPOSITIONS:

This study was guided by the following propositions:

- The knowledge of PLWHAs on CHBC plays a significant role in guiding their perceptions on what that care entails for them.
- The extent to which PLWHAs participate in facilitating their care at home is important in determining what perceptions the PLWHAs hold of CHBC.
- Perceptions of PLWHAs are closely guided by the extent to which CHBC services respond to their priority care needs.

- Problems encountered in providing CHBC may significantly dampen the perceptions of PLHA on benefits in receiving care at home.

CHAPTER THREE

RESEARCH METHODOLOGY

This section describes the research procedures including data gathering techniques, sampling procedure, sites of survey, unit of analysis analytical techniques, and methodological problems encountered during the process of investigation.

3.1 SOURCES OF DATA

Both primary and secondary methods of data collection were used. This being an exploratory investigation which sought to investigate a fairly new theme about which very little is documented the necessity of the two data types was considered. In actual fact, while much literary work has been done on elements and importance of CHBC, including explicit guidelines for ensuring Quality of Care, there is still little known in terms of PLWHA and other beneficiary perception of CHBC.

Because the focus of this study was specific to CHBC interventions, the study drew a lot from some existing CHBC projects' literature sources which included research articles, journals, reports and other publications.

Ulin et al (2002) emphasizes that as a secondary data source, documentary research, conducted through reviewing and analyzing data from existing documents can add immeasurably to the researcher's understanding of the context of the research. There are vast amounts of project related data pertaining to CHBC interventions, mainly in the Kenyan situation for example, the COPHIA project in Coast Province and the HAPAC project in Nyanza project. These provided earlier essential pointers to perceptions by PLWHAs on CHBC. Desk research, conducted through review of project documents also provided practical data on how target beneficiaries have responded to CHBC far and was essential in triangulating the validity of data obtained from field research. Primary data relevant to this study was also collected. This was done by use of questionnaires and key informant interviews.

3.2 Site of the study

This study was conducted in Kangemi location, a low-income level suburb located within the greater Westlands Division, Nairobi province, Kenya. While the researcher acknowledges the presence of CHBC interventions in various parts of the country, a Nairobi site was selected owing to constraints in time and financial resources. There are seven villages within the Kangemi slum namely Waruku, Gitoka, Gishagi, Dam, Mushegwe, Nthong'o and Bottomline. Kangemi has one of the largest slum based interventions in HIV/AIDS e.g. the Lea Toto program, which began in 1999 and targets at least 1000 families of persons living with HIV. HIV prevalence in this area is xxx 16% (KDHS, 2003). Given the prevalence rates and the presence of relatively established CHBC programs, this area was considered appropriate as it was representative of an ideal context demanding CHBC interventions.

3.3 Sample selection and sample size

Four villages out of the seven villages were selected using a purposive sampling method. This purposive selection aimed at obtaining a homogeneous sample of respondents who had been involved in CHBC and who were able to provide valid personal information as relates to the study topic.

The target population in this study was the HIV-infected and affected population of Kangemi location served by the existing CHBC interventions. The target was PLWHAs as primary beneficiaries of the CHBC interventions. The sampling frame in respect to this population essentially included people infected with HIV and/or living with AIDS.

This sample was drawn from existing CHBC (PLWHAs) members within the Kangemi slum area. Existing PLWHAs' Support groups were the point of entry as these represent PLWHAs who had gained a more positive acceptance of their HIV sero status and were therefore open to participate in the study discussions relating to their health.

The sample drawn for this study was representative of the target population. This was achieved by ensuring inclusion of any significant heterogeneous subjects, primarily

PLWHAs who had been involved in CHBC for at least six months. The overall study target population was homogenous in regard to the CHBC interventions, given that the PLWHAs selected in the sample participated to a reasonably uniform degree in the CHBC intervention as target beneficiaries.

An initial contact with CHWs established that support groups were available in only four of seven villages, hence these villages were purposively selected. Once the support groups from within the four villages had been identified, all four groups, with a membership of 10-15 members were listed to comprise the sampling frame. For each group, an initial consent was sought from the support group leaders to help identify respondents who would be willing to participate in the study. Through a snowballing identification process, a group leader identified 2-4 group members at the start as respondents. Each of these then subsequently identified one or two other persons for interviewing. A few of the respondents identified through this snowball approach had not yet joined the support groups but they bore close links with existing support group members. Although the proposed sample size was ninety respondents, only seventy respondents became available ultimately. This was occasioned by a number of factors discussed at a later section in this chapter.

3.4 Unit of Analysis

The unit of analysis in this study was the perceptions of PLWHAs.

3.5 Data Collection

In this study, four methods of data collection were used. These included face-to-face interviews, key informant interviews, observation and review of documentary materials.

These were used as described below:

3.5.1 Face to face interviews

The interview schedule was the major means of data collection. A questionnaire was the interviewing tool and consisted of questions formulated as per the objectives of the study.

The questionnaire had 40 questions in total, of which 9 were open-ended and 31 were

closed ended. This questionnaire included both structured and non-structured questions. The non-structured questions were aimed at probing for a wide range of responses. They offered a better understanding of the perceptions of PLWHAs and gave the investigator an opportunity to probe for further clarifications whenever appropriate. The structured questions were confined within standard issues under investigation such as the aspects of CHBC as contained in national HBC guidelines. The questionnaire was developed in English language but in most cases the interviews were conducted in Kiswahili language depending on the level of education and language proficiency of the respondent.

This study was carried out between the months of April and May 2004. The questions were administered to the respondents through direct personal interviews. The researcher conducted this study personally due to the fact that it is a sensitive study, requiring adherence to respondent confidentiality and also in order to be able to clarify and explain questions just in case a respondent did not understand. The interviewer made the necessary formal introductions to the respondents with the help of the CHBC support group leaders. The researcher began by explaining the purpose and importance of the study to the respondent. Further, the researcher assured confidentiality of any information volunteered by the respondent and requested for an oral consent from the PLWHA to participate in the interview.

A good rapport between the respondents and the researcher was established and they in turn were able to give objective responses with ease. This was necessary in order to help the respondents be at ease (bearing in mind the sensitivity of the topic of discussion) so that the interview would go on as scheduled. Each interview lasted 20-30minutes. At the end of the interview, the interviewer thanked the respondents for their indulgence.

3.5.2 Key Informant Interviews

Unstructured interviews were conducted with ten CHWs who were considered key informants in respect of their involvement with facilitating CHBC for PLWHAs. Only one of ten CHWs was male, this being because men rarely volunteered to serve as CHWs. These key informants were drawn from the same villages that the PLWHA

respondents were based. Most CHWs had served in earlier community programs, particularly as community based distributors (CBDs) of family planning services and later on joined CHBC service.

Like the PLWHAs, identification of CHWs was done through snowballing. The CHWs interviewed had prior involvement with CHBC for over one year in the Kangemi slums. Their responses were instrumental in triangulating what the PLWHAs reported.

3.5.3 Direct Observation

In the course of the interviews, the researcher observed non-verbal aspects of the respondents to complement the spoken responses. Whilst reporting on their health conditions, the researcher was able to observe varied manifestations of health conditions e.g. coughs, sighs, skin conditions, and general malaise. There was evidence of congested housing, with most PLWHAs residing within close proximity of one another.

The general living conditions depicted a fairly low economic status, with the single-roomed housing holding just bare necessities. Majority of respondents were involved in informal livelihoods, and interviews had to be scheduled to fit within the times that the respondents would be done with their commercial laundry or other chores.

An important observation was the close fraternity shared by members of support groups, indicating an important source of their strength. Their positive attitudes to positive living was also evident in the manner in which they opened up to discuss intricate issues of their lives.

3.5.4 Review of documentary material

In trying to consolidate responses, particularly from the open-ended questions, reference was made to national HBC guidelines, policies and handbooks as well as to other CHBC project documents to help link the information to standard practice or given protocols. This proved particularly essential in coding the open-ended questions as well as the unstructured interviews.

3.6 Problems encountered in the field

This study was carried out between the months of April and May 2004, which were characterized by a very rainy weather. This rendered access within the Kangemi villages very difficult as well as caused a lot of discomfort in manouvering through the lean access routes. There were also delays occasioned by heavy rains, thus delaying the timing of the interviews considerably.

As earlier mentioned, the respondents were heavily involved in seeking out casual work opportunities and hence the scheduling of their interviews was dependent upon their availability, usually in the later afternoons.

On introducing the topic and purpose of the study, respondents' expectations were raised and many voiced their hopes of expecting gainful returns to their input.

3.6 Ethical considerations

Overall, any form of a direct labeling of people as PLWHAs was disallowed in this study, hence the researcher followed a systematic selection to identify appropriate respondents, with the help of local stakeholders by primarily ensuring a respondent's willingness to participate in the study. The entry point to obtaining concurrence was through program officials and other community counterparts e.g. community health workers (CHWs) who had a close working relationship with the PLWHAs and through whom the PLWHAs' initial consent for participation in the study was given. The study objectives were discussed with both the CHBC program officials as well as with CHWs. The researcher then ensured she obtained an informed consent for PLWHA participation in the study by each respondent prior to each interview by clearly outlining the purpose of the research, explaining the purpose of the research and procedures that were used in selecting them to participate in the study. The data collection procedures were then explained to the respondents and their voluntary participation requested. Participants were assured of the study's sensitivity in maintaining the study subjects' privacy and confidentiality.

The questionnaires and interview schedules did not bear any identifiers such as names, contact information or plot/house numbers that would permit the client to be identified in any way. An oral informed consent was then sought before proceeding with the interview.

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

This chapter presents the analysis of the research findings using descriptive data. The first set of data presented includes the demographic variables of respondents. In the second section, the data gathered from the eighty interviews (70 respondents and 10 Key informants) is presented and analyzed in line with the study objectives. Data is presented by use of percentages, graphs, tables and charts in a bid to describe the perceptions, relationships, challenges and experiences of PLWHAs in CHBC. Data from CHWs is interlinked with that of PLWHAs and meaningful relationships drawn out. Propositions stated in the previous chapter are appraised to ascertain the relationships that exist between the dependent and independent variables. Various variables were used to gather data on the four stated propositions and these will be discussed in the section below to explain their relationships based on this study.

4.1 Demographic variables of respondents

There were 70 individual interviews conducted with PLWHAs and 10 Key Informant interviews conducted with CHWs. 56 (80%) of respondents were female and 14(20%) were male as depicted in the Table below:

4.1.1 Sex of PLWHAs

Table 1: Sex of respondents

Sex	n	Percentage
Male	14	20
Female	56	80
Total	70	100

Only one of the ten CHWs interviewed in the key informant interviews was male. This is because this respondent was the only male who was identified as a CHW in the study area. Similarly, there were only 20% men identified by their PLWHA colleagues for

interviewing. The gender involvement of respondents in this study is an important indicator of the greater involvement of women in CHBC, not just as caregivers but also as clients. It also confirms that women are more open about their HIV status as seen through their involvement in support groups, hence they were more accessible for interviewing. It therefore follows that women have a greater likelihood of finding opportunity to learn about HIV/AIDS issues, take better care of themselves and of each other and whenever possible, access services available to them e.g. medical care. This finding is consistent with the general thinking that HIV has to a great extent assumed a woman's face, as depicted in the Kenya demographic and health survey (KDHS 2003) analysis in which striking gender differences were noted among young people.

4.1.2: Age of PLWHAs

The mean age of respondents was 37.69 years, with a median age of 38 years and a standard deviation of 8.934. The youngest respondent was 19 years and the oldest/maximum 63 years. While it is right to say that the AIDS pandemic has not spared any age, the more productive age bracket of 19 – 45 has been severely affected. Young people within the reproductive age are most vulnerable to HIV infection, as evidenced by the KDHS 2003 findings.

Table 2: Age of respondents

Age Interval	n	Percentage
19-29	14	20.0
30-39	22	31.1
40-49	28	40.0
50+	6	8.9
Total	70	100

Relating to the family size of respondents as analyzed below, the effect of a HIV positive condition for people in this productive age group is an increased burden of care both for themselves as well as for their children.

4.1.3: Number of children

The mean number of children living with respondents in the study was 3.12, while the mean number of children they had in total was 3.97. Seven respondents did not report having any children. The number of children points towards the burden of care that PLWHAs have over providing for their children, this being against a backdrop of a prominent inability of PLWHAs to fend consistently for their livelihoods. Despite the challenges faced by PLWHAs in caring and providing for their children, children are a key motivator for PLWHAs' quest for continued living. *'my child is an inspiration for me to carry on'*, cited a thirty-four year old female respondent. Similarly, a prominent perception of PLWHAs regarding their desired means of having CHBC improved included social support, particularly the provision of educational support for children of ailing PLWHAs. One of the means perceived by PLWHAs as a break through to resolving their challenges was the acquisition of an educational sponsorship support for one's children, either by program support or by friends and family.

Table 3: Number of living children/children living with respondent

No. of children	Number of living children		Number of children living with respondent	
	n	Percentage	n	Percentage
1-2 children	15	23.7	20	39.4
3-4 children	30	47.4	24	45.5
5+ children	18	28.9	8	15.2
Total	63	100	52	100

In spite of the low socio-economic conditions of respondents, 71% of school-going age children were reported to be attending school. This is mainly attributable to the universal free primary education that was introduced in Kenya at the beginning of 2003. However, in the same environment, secondary school level children were more likely to drop out of school owing to the high cost of schooling involved at that educational level. The lost opportunity of a secondary school education is a precipitate to a cycle of poverty that the parents are undergoing.

An observable phenomenon is that PLWHAs may not have all the children living within the household. 26% of respondents did not have their children living with them for a variety of reasons; some of these children may have been grown up and living on their own. Some of the other reasons directly relating to the state of PLWHAs was that they usually were the household heads and breadwinners who had lost their sources of income due to frequent illness. Consequently, children either ended up living with close relatives or may have been sent off to fend for themselves. One twenty-nine year old female respondent reported that she sent away her children 'wajitafutie' i.e. to fend to themselves.

67% of respondents had lived in Nairobi for between 10-40 years, implying that most of them were indeed born and bred in the city. This would therefore mean that their social support systems are largely based within their city suburban residency as there may be limited association or dependency with rural social systems.

4.1.4: Education and Employment

Majority of respondents had received a formal education up to primary school level (49%) or secondary school level (38%). Only 13% had never had any formal schooling at all.

A 51% majority were self employed in the informal sector, mainly involved in casual labor such as doing laundry work for the up-market neighborhoods. 22% were dependent on family and friends for their livelihood. Only one person in the entire sample had a salaried form of employment.

Table 4: PLWHAs' Source of income

Source of income	n	Percentage
Self employed	39	55.6
Dependent	16	22.4
Salaried employment	1	2.0
Other (some family support or no income)	14	20.0
Total	70	100.00

These unstable sources of livelihood were characteristic of poverty, which is both a cause and result of vulnerability to HIV infection as well as a result of HIV infection (World Bank 1997). The informal sector in which PLWHAs earn their livelihood is a further strain on their ability to work and earn a living because the work is strenuous and is quite dependent on their health. Asked concerning the things that they are not able to do for themselves, a leading majority of 52% reported that they experienced difficulties in doing 'any strenuous work'. The bulk of their livelihoods, as indicated above revolve around doing menial strenuous work such as washing clothes, fetching water, walking long distances, carrying heavy loads and all manner of household chores, all of which require a healthy body to facilitate performance. This therefore implies that the health condition of PLWHAs impacts negatively on their ability to consistently earn a living.

Related to the above concerns about strenuous work, 8% and 6% respectively stated that they could neither work long hours nor could they engage in work to earn an income, both resultant from their state of long periods of illness. An additional reason explaining the limitations cited was that they became easily fatigued and primarily lacked capital to start up any income generating activities.

For PLWHAs who did not suffer any debilitating illness, 33% reported that they were able to do virtually anything they desired and hence their livelihood was not affected.

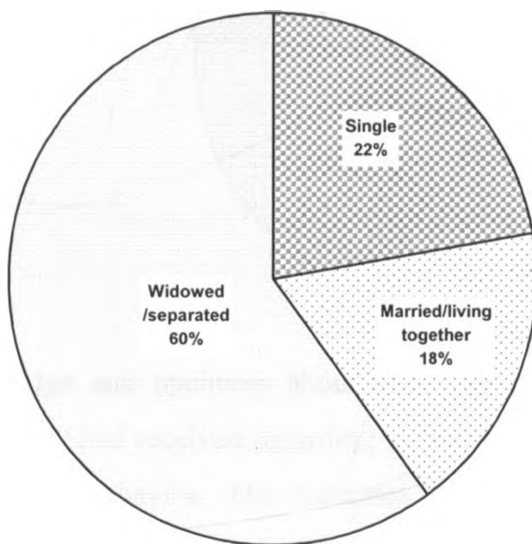
4.1.5: Marital Status

In this study, marital status seems to bear a significant relationship to HIV infection. Widowed and separated persons take a leading 58% while single persons were 22%. Of the total persons interviewed, only 18% were in a marital union. Respondents reported that the knowledge of HIV infection was in itself a reason for a marriage break up. Women reported that it was common practice for them to be ejected from their matrimonial home once discovered to be HIV positive. On the other hand, separation for those married/living together sometimes became a necessary option for women given that men may not have been readily willing to consistently use the male condom to prevent

HIV transmission. This scenario for adopting safe sexual behavior between spouses was further compounded by the fact that men were reported to deny their HIV + status 'even on their death beds', as described by a forty-two year old female respondent.

The high percentage of single and unmarried persons, (22% and 60%) interviewed correlates to their sexual orientation of multiple sexual partners. This is indicative of their perceptions that CHBC has been useful in teaching them about HIV prevention by helping them adopt safer sexual behavior.

Figure 1: Marital status of respondents

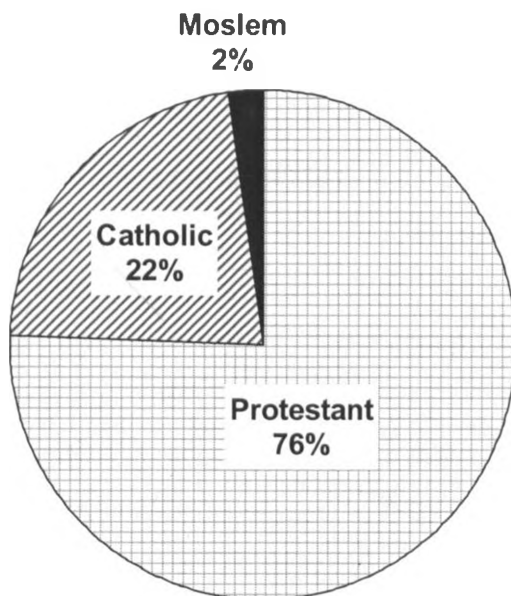


Data gathered from this study indicated that it was common for women to discover their HIV sero status during their pregnancy, presumably through the on going national efforts of Prevention of mother to child transmission (PMCT) of HIV. Women who had such meager incomes were bound to experience greater vulnerability to indulge in transactional commercial sex work, indulge in marital or sexual relationships for convenience and have limited bargaining power for safe sex.

The affiliation to different religious denominations in the study sample indicates membership of different faiths in the support groups. This however may not be

generalized to the general public to reflect the proportions with which different faiths have been affected by HIV/AIDS. The underlying observation however is that religion played an important role in the spectrum of CHBC.

Figure 2: Religious affiliation of respondents



The knowledge and openness about their HIV sero status, coupled with the CHBC instruction they had received regarding care of themselves was important in encouraging a health seeking behavior. This reiterates the need for 'healthy' persons to seek to know their HIV sero status for the dual advantage of instituting early health care as well as a HIV prevention strategy. Clinical recommendations of diagnostic counseling and testing (DCT) as well as the 'opt-in' approach in the prevention of mother to child transmission (PMTCT) are equally important as respondents described these two avenues as the ways through which they got to learn of their HIV sero status. The additional advantage to any of the three ways through which a HIV test result was given to a client was that it was essential for stigma reduction, hence the PLWHAs began a process of accepting to live positively.

4.1.6 PLWHAs' Health

As would be expected, PLWHAs are faced with a myriad of health problems, with 73% of respondents describing their health as 'average' i.e. not too good and not too bad.

Though none of the respondents were too severely sick to be bed-ridden at the time of the interviews, 16% described their health as bad, and 11% said their health was good.

Opportunistic infections including Sexually transmitted infections, diarrhoea, oral thrush, colds and pulmonary tuberculosis/pneumonia or other chest related illnesses were the majority of cases reported (49% and 46% respectively) by respondents. Other illnesses including cancers, general malaise, kidney disorders and frequent headaches comprised 36% and skin disorders 8%)

Table 5: Illnesses commonly suffered by PLWHAs

Illness category	n	Percentage
Opportunistic Infections	25	35.2
TB/Pneumonia/other chest complaints	23	33.3
Skin disorders	4	5.6
Other(no recent illness)	18	25.9
Total	70	100

The openness of PLWHAs regarding their illness was important in aiding a good health seeking behavior. The achievement of good or average health was linked to the timely and comprehensive treatment of opportunistic infections and may also be linked to a comprehensive course of treatment. Most respondents had been to see a doctor on average in the preceding two months, owing to various ill health conditions.

Given the low socio-economic status of the majority populace in Kangemi, there is an absolute need to improve accessibility of health services, particularly in the light of the needs of PLWHAs.

4.2 ANALYSIS BY OBJECTIVES

4.2.1 PLWHAs' knowledge and perceptions of the role of CHBC in the provision of their care.

PLWHA Knowledge of CHBC

All the respondents interviewed were aware of CHBC and the role it plays in the lives of PLWHAs, including those sick people at home as well as the relatively healthy. In this study, all the 70 respondents reported they had learnt through one way or another about good nutrition, hygiene, nursing/clinical care, counseling/psycho-spiritual care and infection prevention. Some CHWs had taught PLWHAs about CHBC issues while others had acquired plenty of knowledge through information disseminated at the support group meetings. Generally, the study reveals that PLWHAs involved in CHBC had adequate knowledge about what this service entailed for them. Nutrition was the most prominent element in CHBC that PLWHAs reported to have been taught about, with the next in prominence being infection prevention as shown in the Table below:

Table 6: PLWHAs' knowledge of CHBC issues

Category	n	Percentage
Nutrition	62	28.6
Infection Prevention	53	24.3
Counseling/Psycho-Spiritual care	42	19.3
Hygiene	30	13.6
Clinical Care	19	8.6
Nursing care	12	5.7
Total	218	100.00

PLWHAs' Sources of Knowledge of CHBC

In terms of imparting knowledge to PLWHAs, the CHW is the single most important medium through which PLWHAs learn about CHBC. As illustrated in the table above, PLWHAs have a wide scope of knowledge about CHBC, drawn from a variety of sources. Consistent with National HBC Policy guidelines (2002), respondents interviewed had a reasonably good understanding of the various components of CHBC, including Clinical care, Nursing care, Counseling and Spiritual care and social support. This study established that PLWHA involvement in support groups is significant importance in both providing psychosocial support to its members as well as being a focal point at which PLWHAs find an opportune moment to provide peer education on healthy living. Support groups therefore play a leading role in educating its members about the elements of CHBC, as do health care providers. It was evident that program staff had a minimal involvement in directly educating PLWHAs about CHBC. All these players combined have provided PLWHAs with a good understanding of CHBC issues as presented in the Table below:

Table 7: Sources of information on CHBC

Category	n	Percentage
CHW	49	36.6
Support group	43	32.2
Hospital	33	24.1
Program Staff	8	5.7
Other	2	1.1
Total	135	100

The data on sources of CHBC information is positively complimented by responses from CHWs who reported that they had a major involvement in teaching PLWHAs and their families about CHBC. Though CHWs also reported involving family members as well to facilitate their participation in CHBC, it is evident from this study that there lacks sufficient openness between family members and PLWHAs. PLWHAs do not therefore necessarily discuss aspects of care with their family members. Their limitation may be

influenced by stigma and denial at family levels, as one 30-year old female CHW reported that *'the family members get very hostile to us (CHWs) when we visit their homes for the first time'*. This is in line with the fact that only 16% of PLWHAs knew of the involvement of their own family members in being taught about CHBC, with 80% of respondents reporting that their family members were not involved at all, and 4% did not know whether there was any involvement of these or not.

PLWHAs' Perceptions on the role of CHBC in provision of their care:

Drawing from the above findings, the knowledge that PLWHAs have of CHBC leads them to perceive that CHBC has a significant role to play in facilitating their care at home. PLWHAs therefore perceive CHBC as playing the following roles in their lives:

Table 8: Role CHBC plays in the lives of PLWHAs

Category	n	Percentage
Positive Living	43	45.2
Health improvement	22	22.6
Self Care	15	16.1
HIV Prevention	15	16.1
Total	96	100

The most prominent role mentioned as attributable to CHBC was the enhancement of positive living. Respondents described their involvement in CHBC as a 'moral booster that gives hope'. Their participation in support groups helped them realize that they were not the only ones in that situation and that way, it helped them gain hope both for healing and for continued living. The adoption of a 'stress free life' as they described it is important for the PLWHAs because it aids the acceptance of their status as well as helps them live longer, given that in their view, **'it is stress which makes people die fast'** reported a 38-year old female respondent.

When asked about how PLWHAs perceived CHBC, the ten CHWs reported that there was a general acceptability of CHBC by PLWHAs. This is because it helped PLWHAs

feel that there is someone who cared about them and that they were not discriminated against after all. Dependent upon the extent and ways in which CHWs got involved in caring for PLWHAs, particularly if they provided material utilities, they were highly valued by PLWHAs who looked up to them as their source of livelihood.

A good health seeking behavior, which drove the PLWHAs to seek medical treatment at the earliest occurrence of illness was recognized by PLWHAs as a positive result of CHBC and one that aided the maintenance of good health. However, in as much as the PLWHAs knew how to take care of themselves in the home and community setting, including the necessity of health care, they found it increasingly difficult to meet their needs. A hindering factor was lack of finances. Without money or a stable income, one was not able to eat healthy or seek medication. Observations made in the field and available data in the study revealed that most PLWHAs in the study were either casual workers or self-employed and (as would be expected), bore major financial constraints. Resultant from this knowledge, some respondents had been able to access Anti Retroviral (ARV) and prophylaxis treatment, though a majority had not been able to access any such medication. PLWHAs who had access to medication were well versed with the importance of drug adherence and issues relating to the facilitation of a quick recovery. Over all, all respondents had knowledge and a desire for ARV treatment to improve their health.

Another issue that emerged prominently in the study as an important role played by CHBC is the promotion of safe sex and condom use by PLWHAs in HIV care and support. As stipulated in WHO/UNAIDS guidelines on Key Elements in HIV/AIDS Care and Support (2000), health services should be used to support preventive behavior and to promote safe sex or condom use. Respondents cited the promotion of safe sex as a predominant role that CHBC played by educating its members.

In spite of the financial constraints surrounding the provision of CHBC, PLWHAs were well aware of the need to ensure self-care particularly through ensuring they strived to eat nutritious foods and by maintaining a good personal hygiene.

It is however noteworthy that the initial phase at which CHWs introduced CHBC to PLWHAs was a difficult process, both for CHWs in getting accepted by the PLHAs and family to get involved in their sensitive health affairs. On the other hand, PLWHAs faced an unprecedented difficulty of accepting their health status and opening up to receive external help from a non-family member. Some retorted to CHW visits with hostility, denial and resignation by preferring to be left alone 'because they were going to die anyway'. While this dissonance is a normal psychological process in the ultimate acceptance of a HIV-positive condition, it points towards the need to strengthen the counseling and communication skills of CHWs in this regard.

In the light of these discussions, it is evident that PLWHAs have sufficient knowledge about CHBC and this understanding therefore guides their perceptions about the role of CHBC in their lives.

4.2.2: The level of involvement of PLWHAs in CHBC.

As earlier mentioned, the involvement of PLWHAs for participation in CHBC is primarily through CHWs, whose major role is to teach the PLWHAs and their family members on how to take care of themselves and their infected kin. Other roles of CHWs include providing general guidance to PLWHAs and their families on nutrition, drug adherence, healthy living, and offering basic counseling. Their involvement from time to time may extend beyond this advisory role to practically undertaking chores to support the PLWHAs e.g. cooking, washing clothes and feeding. CHWs reported a common expectation placed upon them to provide food and utilities to the PLWHAs, an issue that forces them to expend their own resources for this cause.

Based on the knowledge that PLWHAs possess regarding CHBC, they are consciously involved in taking care of themselves at home to ensure healthy living. Their involvement in support groups is a critical means of ensuring that they draw psycho-spiritual support provided in group therapies. As earlier mentioned, the support groups also play a key role in providing education to PLWHAs on how they need to take care of

themselves. Asked what they did to ensure they were taking care of themselves, respondents reported the following efforts as outlined in the Table below:

Table 9: What PLWHAs do to take care of themselves

Category	n	Percentage
Good diet/hygiene	53	43
Safe sex	28	22.8
Seek medical help	26	21.5
Psychosocial support	16	12.7
Total	123	100

In as far as PLWHAs were healthy, they were able to do as much for themselves as they possibly could, hence 33% of respondents at the time of the study reported they could do virtually everything for themselves. However, in times of ill health, some of the reported limitations in being able to take care of themselves included an inability to do strenuous work, which a majority 52% reported. Related to strenuous work were specific limitations such as working long hours and being unable to earn an income primarily owing to long periods of illness. Based on observations and discussions in the course of field work, it was noted that a majority of respondents were involved in relatively strenuous work such as doing manual laundry for up market neighborhoods, fetching water for sale at homes and at construction sites and undertaking businesses that may require carrying heavy loads e.g. green groceries. These also apply to similar household chores performed on a day-to-day basis. Additionally, they had to walk long distances to seek the menial jobs and to save on transportation costs. As noted on the profile of illnesses suffered by respondents in this study, the prevalent chest pains/ chest-related illnesses caused PLWHAs specific difficulties in performing strenuous chores. These limitations are outlined in the following Table:

Table 10: Things PLWHAs are not able to do for oneself

Category	n	Percentage
Straining work	39	52.1
Working long hours	6	8.3
Earning an income	5	6.3
Missing	25	33.3
Total	75	100.00

Besides their personal involvement, a varied lot of people involved PLWHAs in the things they did concerning them. The support groups recorded the greatest level of PLWHAs involvement, as these were the primary avenues for their involvement in CHBC. Others who involved PLWHAs in aspects of care and support included CHWs and family members as discussed in an earlier section. From this study, it is evident that there is a lesser involvement of hospital-based staff and friends in the course of CHBC.

Table 11: People who involve PLWHAs in CHBC

Category	n	Percentage
Support Group	48	33
Family member	39	26.6
CHW	29	20.2
Hospital staff	16	10.6
Church/FBO	8	5.3
Friend/neighbor	6	4
Total	146	100

The involvement of PLWHAs in various aspects of CHBC has created in them a keen interest and a desire for a greater involvement in issues relating to HIV prevention and care. Asked whether they would have liked to get more involved in HIV/AIDS matters, 46% of respondents indicated a willingness to learn more on HIV/AIDS, particularly to

help them acquire a wider understanding about HIV treatment issues and the avoidance of opportunistic infections. Such knowledge would not only serve to improve their health and self care but would also have a positive spill over to facilitating peer education. Respondents were overly appreciative of their involvement in support groups and felt there is much more that they would like to do within the confines of their support groups, including encouraging others through counseling, visiting the sick and offering the requisite home care. Other desirable ways expressed for their involvement included mobilizing communities to increase HIV/AIDS awareness, educating people on treatment and care to enhance HIV prevention and care efforts. Owing to their financial handicap, respondents voiced their need for support that would facilitate their involvement in income generating activities and subsequently improve their well-being. The percentages of these responses are outlined in the Table below:

Table 12: Desirable ways for more involvement of PLWHAs

Category	n	Percentage
Learn more on HIV/AIDS	34	45.8
Support group involvement	15	20.8
Educate people on AIDS	14	18.8
Financial/IGA assistance	11	14.6
Total	74	100

The extent to which PLWHAs participate in facilitating their care at home is therefore important in determining the perceptions they hold of CHBC.

4.2.3: Priority needs which PLWHAs perceive as key for CHBC interventions.

Asked about what needs they considered important for CHBC, respondents cited clinical needs, nursing needs, counseling/spiritual care needs, social support and other material needs, all to varying degrees. In respect to the needs mentioned, respondents were asked to mention to what extent they considered the said needs were available to them. Their responses are presented in Table 13:

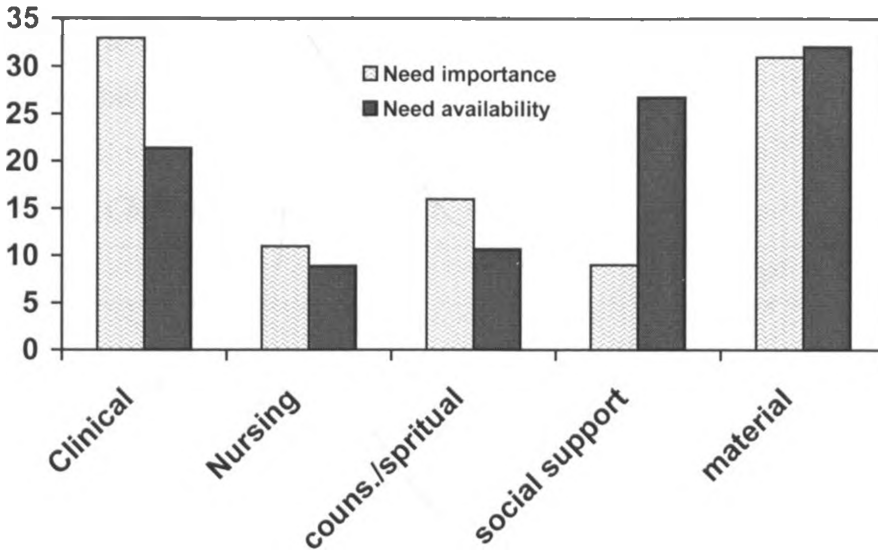
Table 13: Important needs versus available needs

Category	Important needs in CHBC		Availability of said needs	
	n	Percentage	n	Percentage
Clinical needs	66	33	12	21.4
Other (material needs)	62	31	18	32.1
Counseling/spiritual care	32	16	15	10.7
Nursing needs	22	11	6	8.9
Social support	18	9	5	26.8
Total	200	100	56	100

Based on the findings of this study, it is evident that PLWHAs' perceptions about their priority needs in CHBC are closely linked to the availability (or lack) of those services. Hence, respondents identified clinical needs (34%) and other material needs (32%) e.g. Information, education & communication materials, food and shelter as highly important. These services/goods are available in varied proportions of Clinical needs (21%) and material needs (32%). Overall, all the needs identified depict a scarce resource availability, relating to earlier evidence that PLWHA knowledge and involvement is limited by resource availability. The social support needs show a skewed relationship of an availability of resource exceeding the needs cited. This is most likely influenced by the combination of factors cited in Table 11 above, which may imply that the combined role of CHWs, family and friends enables PLWHAs feel that their social support needs are reasonably covered.

Based on a cross-tabulation analysis, it is evident that religious affiliation affects the perception of the need for spiritual care. 47% respondents identified counseling/spiritual support as a priority need. Likewise, 98% of respondents who had reported a good, bad or average state of health identified clinical needs as important in the CHBC spectrum.

Figure 3: Need importance vs need availability



4.2.4: Challenges and experiences of PLWHAs in CHBC.

Various challenges reported by the PLWHAs in relation to the provision of CHBC include; limitations in accessing nutritional support, lack of material resources such as shelter, limited access to clinical care and referrals, and stigma. Similarly, CHWs reported related challenges that they knew were experienced in CHBC.

Nutrition was considered as the greatest challenge that adversely affects the attainment of CHBC goals. This is because respondents considered it as important for the maintenance of good health as it is for drug/treatment efficacy. Not only was availability of a good nutrition a challenge but a steady availability to food was not guaranteed owing to an unstable income. Alongside this, limitations in access to clinical care and referrals, mainly due to the cost-sharing policies in public hospitals posed a major challenge to PLWHAs.

As earlier discussed, PLWHAs often lost their source of income when they were in bad health, which was the case more often than not in their lives, consequently leading to a chronic lack of material resources. Housing posed a major challenge and was repeatedly

echoed by respondents as a major concern. At the time of the interviews, some respondents had been evicted from their rented houses. This caused a consequential detriment to their psychological and physical health. These challenges are summarized in the Table below:

Table 14: Challenges faced in CHBC

Category	n	Percentage
Nutrition	63	32.3
Material resources	44	22.6
Clinical care/referrals	44	22.6
Stigma	36	18.5
Other	10	5
Total	197	100

Stigmatization did not feature as a prominent challenge and respondents explained that PLWHAs would ordinarily suffer stigma when they developed full-blown AIDS, hence a state of HIV infection alone remains a confidential status and does not subject one to stigma. In the absence of late-stage AIDS disease, PLWHAs would otherwise have no reason to disclose their HIV status to other people other than their support group members who offered peer support. In fact, owing to the recognition that stigma would affect not just themselves but their family members, PLWHAs reported taking on a protective role of their families by not divulging to them the truth about their HIV positive status. One 39-year old female PLWHA reported; *'I have kept the issue of my status a secret from my family as this would stigmatize them'*. PLWHAs therefore felt that whereas they had come to terms with their HIV status, they held a responsibility of protecting their loved ones from stigma that would result from the knowledge that some of their family members had the HIV.

Support groups play a key role in helping PLWHAs cope with their HIV status. A primary way that these groups became effective was through *"removing stress, which usually is what kills people"*, reported a 38-year old female PLWHA. Isolation and the

lack of emotional and social support was detrimental to the lives of PLWHAs. Their close-knit social support groups were therefore a social cushion upon which they could offer one another peer support.

Another challenge surrounding CHBC related to involving PLWHAs and their families in CHBC due to the apparent stigma that blocked the establishment of rapport between the CHW and the PLWHAs and their families. CHWs reported that 'some families are rude', that 'they think CHWs are looking at them as fools' and 'they chase you away, especially if you have not brought anything for them'.

Children, their education and upbringing was an important concern in the minds of PLWHAs, both in their lifetime as well as when they become orphaned. PLWHAs thought of relatives as the ideal familial institution that ought to take care of children orphaned as a result of AIDS. However responses in the study indicated that they were also wary of the economic strains this would impose on carers and hence the high costs of living would not easily permit such arrangements. There was therefore a hope that the government would come up with ways of building institutions that would help cater for their children in the event of orphanhood. This finding is important because it challenges the popular belief and NASCOP/OVC principles which advocate for strengthening the protection and care of orphans and other vulnerable children within their extended families and communities.

Despite all the challenges faced by PLWHAs in the quest for CHBC, their perceptions were nonetheless not dampened. They upheld a positive perception that the effectiveness of CHBC would be realized if they were provided with a sustainable source of income to enable them meet their basic needs as identified. Moreover, this optimism led them to take positive steps in a bid to overcome their challenges as follows:

Table 15: How PLWHAs tried to overcome challenges in CHBC

Category	n	Frequency
Involvement in work/ keeping busy	40	38.8
Psychosocial support	27	25.4
Solicit support from family & friends	23	22.4
Seeking medical assistance	14	13.4
Total	104	100

In spite of unstable incomes and a usually unpredictable health status, PLWHAs strive to sustain their business and other work even in sickly conditions. This drive is fueled both by the absolute necessity of earning an income as well as by the need to keep the mind busy and not wondering off into depressive thoughts. Linked to this emotional motivation, the respondents reported psychosocial support as an all-important factor for ‘relieving stress’. There were underlying motivational factors such as children, whom PLWHAs focused on as their inspiration. Their ardent believe in God was particularly a strengthening factor for a majority of the respondents who believed there was still hope for them as long as they believed in God. Salvation and spiritual activities both at personal levels and with support group members formed part of the support group therapy activities. There was also a conscious effort on the part of the PLWHAs to avoid any stigmatization by for instance exuding confidence to snub ‘gossipy tongues’.

Because of their ability to deal with stigma at personal levels, respondents illustrated openness in confronting their problems through e.g. borrowing food from friends and relatives if need arises. The respondents disclosed that families are supportive of respondents through providing food, finances and other material support. The PLWHAs’ openness about their need had attracted additional support from well-wishers including educational support for children through local development projects.

Well aware of the need to seek prompt medical assistance, the PLWHAs ensured they sought treatment at the earliest opportunity, but not without the expected limitations of

cost related shortfalls. One respondent had tried seeking chemotherapy treatment for a cancer condition but to no avail owing to financial constraints. To enhance their well-being, they attempted a disciplined nutritional adherence, including avoidance of alcohol.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

5.1 Conclusions:

Based on the findings of this study, it is evident that PLWHAs hold a significantly positive perception of the important role that CHBC plays in their lives. Having been taught about the elements of CHBC, they have become involved in taking care of their health and hence their perceptions are guided by that knowledge. This has helped foster a positive attitude and an accompanying health seeking behavior. Despite the many pitfalls encountered in the delivery of CHBC, PLWHAs who already have had a good involvement in CHBC programs maintain a positive outlook to life and believe that the challenges encountered can be resolved.

PLWHAs are widely knowledgeable about CHBC components, with a good nutrition being the aspect that they consider most important. The CHWs are an important medium through which PLWHAs get educated on CHBC, as are support groups. Another important benefit of CHBC in the lives of PLWHAs is its potential to deal with stigma, mainly at personal levels. While this was not seen to necessarily translate to a removal of stigma amongst family members, it points to a need to strengthen and expand counseling beyond the PLWHA to the family members so that more synergy would be achieved in CHBC efforts. This issue was strongly expressed by CHWs in the KIIs who felt that there is a need to educate the general community on the importance of CHBC in order to avoid stigma. They perceived the non-acceptance of CHBC by PLWHAs and their families, particularly in the initial stages as a stumbling block to the delivery of CHBC. In instances where community education had been initiated, CHWs generally reported that *'there is less stigma among those people who have been educated on CHBC'*.

PLWHAs are consciously involved in CHBC. Their participation is however dependent on their state of health so that in as far as they are well, they are able to do virtually everything for themselves. Illness hampers their involvement in CHBC because most of

the work that PLWHAs are involved in is generally strenuous work. Also, illness keeps them away from work, hence interferes with their capacity to work and earn their livelihoods. Overall, PLWHAs express a desire for more involvement in CHBC, particularly by wanting to learn more about HIV and AIDS.

The perceptions of PLWHAs regarding what they consider as priority needs in CHBC are based on whether or not these services are available to them. Underlying the spectrum of challenges faced in CHBC, poverty encompasses them all. PLWHAs expressed an earnest desire to get involved in earning a living that would boost their quality of life.

The most prominent challenge emerging from this study is the PLWHAs' limited access to an adequate nutrition. PLWHAs consider nutrition a very important requirement to boost their health, irrespective of whether they were on treatment.

While CHBC has been deemed a cheaper alternative to in-hospital care, as discussed in the literature review, yet in the long term, it becomes an expensive mechanism of providing care at home, not just for the PLWHAs, their family but also for CHWs who so often have to expend their own resources to provide material items to PLWHAs.

This study concludes that although CHBC has been integrated into the communities, PLWHAs face many challenges and obstacles, the main one being financial. Without financial resources, PLWHAs, their families, health workers and community at large are handicapped in meeting the needs of PLWHAs. Moreover, CHBC should ideally be a multi-faceted programme providing a comprehensive link to all aspects of care and support for PLWHA. All this is achievable except that, as commonly known, the major challenge combating the fight against HIV/AIDS is poverty.

5.2 Recommendations:

Based on the findings of this study, the researcher recommends the following:

- PLWHAs ought to be involved in the design and development of CHBC programs so that in as much as possible, these interventions respond to the needs that PLWHAs identify as their priorities.

- In the light of current government and donor efforts to increase access to ARV treatment and non-ARV treatment for PLWHAs, a social marketing effort should be put in motion to increase PLWHAs' awareness of service delivery points. This would include improving logistical ease for access to these services.
- The level of involvement of CHWs in the practical care of PLWHAs needs to be complemented by involving family members more to have them participate in the care of their loved ones. This would help to ease the burden of CHWs as well as to break the silence amongst family members, which is perhaps the underlying cause of stigma.
- In line with the National guidelines on orphans and other children made vulnerable by HIV/AIDS, an important principle is '...the need to link HIV/AIDS prevention activities, care and support for people living with HIV/AIDS and efforts to support orphans and other vulnerable children' (NASCOP 2003) ". Therefore, in view of the effect of HIV on young parents, the care of orphans and other children made vulnerable by HIV/AIDS needs to be strengthened. CHBC tends to focus primarily on the PLWHA, yet the PLWHA has underlying persistent concerns about 'who will take care of my children when I die'.
- Counseling and spiritual support (whenever required) should be widely availed and recognized as an important component in the spectrum of care and support.
- Nutritional support is a critical need for PLWHAs and serves to enhance treatment efforts. Income generating or other social support mechanisms should be integrated into CHBC programs.
- Counseling and support groups however need to be improved so that these essential services and structures do not only come into play during times of crisis but instead become sustained as an on-going permanent process. Forging healthy sexual behavior norms requires means to sustain them over time.

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