

**MAKING CONNECTIONS: TOWARDS A HOLISTIC
APPROACH TO THE TRAINING OF WOMEN VOLUNTEERS IN
COMMUNITY HOME BASED CARE**

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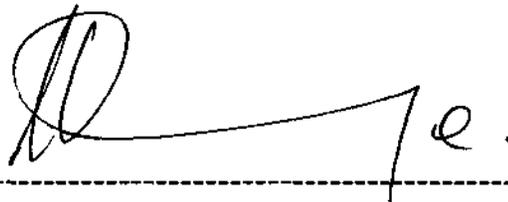
**Submitted in partial fulfillment of the requirements for the Degree of
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DECLARATION OF ORIGINALITY

I hereby declare that this dissertation, which was conducted under the supervision of Prof. Astrid von Kotze, is my original work unless indicated to the contrary in the text.

A handwritten signature in black ink, consisting of a large, stylized initial 'N' followed by a long horizontal line that ends in a small 'e'.

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University of KwaZulu-Natal, Durban
January 2006



DEDICATION

This work is dedicated to the memory of my eldest sister, Sibongile Phungula, who died of AIDS-related causes on 30 July 2003 shortly after the death of her 6-month old baby, Sambulo Phungula.

The entire dissertation, therefore, has been primarily influenced by *firsthand personal experience.*

Rest in peace. Siyohlale sinikhumbula njalo!

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The staff at the AIDS organization in Howick and at the Community Home-Based Care (CHBC) organization in Pietermaritzburg, who granted me permission to conduct this study with the help of voluntary caregivers belonging to them.

I would like to extend my sincere thanks to the CHBC women voluntary caregivers who participated in this study. The entire dissertation came as a result of their readiness and enthusiasm to share their personal stories and experiences. I appreciate their openness and willingness to take risks, making themselves vulnerable with the hope that the achievements and outcomes of the study would be useful in improving the practice of CHBC.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Antiretroviral Drugs
CHBC	Community Home Based Care
CINDI	Children in Distress
COSATU	Congress of South African Trade Unions
DOH	Department of Health
GEAR	Growth Employment and Redistribution
HIV	Human Immunodeficiency Virus
HBC	Home Based Care
KZN	KwaZulu Natal
MRC	Medical Research Council
OVC	Orphans and Vulnerable Children
PLWHA	Person/People Living with HIV and AIDS
SAQA	South African Qualifications Authority
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

ABSTRACT

In the midst of hope and suffering due to the challenges posed by HIV and AIDS in South Africa, communities have literally witnessed a glimmer of hope in women volunteers who have readily and willingly provided care and support to people living with HIV and AIDS (PLWHA) and their families. Policy-makers have maintained that if the care of sick people is to be both comprehensive and cost-effective, it must be conducted as much as possible in the community, with hospitalization only when it is necessary. However, the strains on those caring for people with HIV and AIDS are enormous. This paper argues that neo-liberal policies are reinforcing the divide between the 'haves' and the 'have-nots', by placing strain on women volunteers in the field of community home-based care.

The study was conducted in the area of Mpophomeni Township, in KwaZulu-Natal province. The research participants consisted of 10 community home-based care (CHBC) volunteers and their supervisor, 3 CHBC trainers, and 1 counselling trainer. Using a qualitative design, this study examines a specific CHBC training course and how effectively it prepares voluntary caregivers for the challenges experienced in individual homes. Ascertaining how the training helped caregivers to confront their own fears and problems before dealing with those of others, and exploring how community caregivers coped with the stress inherent in their jobs was the primary focus of this study. For these purposes, a qualitative methodology was deemed most appropriate for it allowed me to gain in-depth information through observations, semi-structured interviews, a review of relevant documents, and training materials.

Inspired by feminist perspectives, the findings revealed that already overburdened and poor people provide the bulk of voluntary services in the area of CHBC. Consequently, they are unable to provide quality care for people living with HIV and AIDS without external support from the government. The findings further established a mismatch between the training content and the reality of work of caregivers. The training puts more emphasis on practical aspects, by providing basic nursing care, often only relevant in helping a bedridden patient. However, many voluntary caregivers reported that the demands placed on them do not end with the death of the patient. This poses a challenge for those in the CHBC training environment as they

need to offer relevant and well-researched information linked to the reality of voluntary caregivers' work. The study also highlighted a need to consider the personal long-term goals of volunteer caregivers and begin to realize the importance of using the training to put them on a career path.

I therefore argue that the burden of care for people living with HIV and dying from AIDS in resource-poor settings cannot be shifted entirely to communities with the false assumption that they are able to cope. As we continue to grapple with moral and ethical issues in the context of HIV and AIDS, we also need to be concerned about moving women volunteers' efforts from invisibility to visibility through a social transformation agenda.

CHAPTER ONE

INTRODUCTION

1.1 OVERVIEW OF THE CURRENT SITUATION

Since South Africa emerged from apartheid and had its first democratic elections in 1994, the country faces new challenges in the post-apartheid era, and that includes among others, the impact of HIV and AIDS¹. Projections on HIV and AIDS have clearly demonstrated that the number of new infections is escalating despite the efforts that have been put in place to curb the spread of the disease (Nelson Mandela/Human Sciences Research Council (HSRC) study, 2002).

According to the National Department of Health's latest National HIV and Syphilis Antenatal Sero-Prevalence Survey (2004), approximately 5.6 million people had acquired HIV infection by the end of 2003. The national Ministry of Health conducted the 2004 annual survey² in all nine provinces, and indications have shown that at a national level HIV prevalence among pregnant women is 29.5% compared to the 27.9% observed in 2003. International consensus remains that antenatal surveys are a useful tool to assess HIV prevalence in areas with high prevalence of HIV and it assists to provide trend data (Nelson Mandela/ HSRC Study, 2002). It is reported that the 2004 survey was conducted at nearly 400 clinics with over 16 000 women attending antenatal care in all nine provinces. According to the survey (2004) the

¹ HIV and AIDS is not the same thing, though they are extremely closely connected. HIV stands for Human Immunodeficiency Virus. This is the name of the virus that is transmitted, through body fluids, from one person to another. The virus can reside in a person for numbers of years without being noticed or felt. Therefore, someone who is HIV positive can be strong and healthy at first, but later on the virus eventually wears down the immune system of the body that helps the body to fight off disease. When this happens a person is said to have AIDS (Acquired Immune Deficiency Syndrome). This is the final stage of the disease. People who have developed AIDS have very little resistance to other diseases (Gennrich, 2004). It needs to be further noted that some authors, in their writing, separate HIV from AIDS, that is, HIV and AIDS instead of HIV/AIDS, to make a clear distinction between the two conditions particularly for awareness and education purposes. In this study, I have also made an attempt to follow the same pattern wherever appropriate.

² This annual survey uses a statistical model to estimate the prevalence of HIV in the population based on the prevalence among women tested at state antenatal clinics.

province of KwaZulu-Natal has the highest prevalence rate at 40.7%, followed by Gauteng at 33.1%. (see Table 1).

Table 1: HIV prevalence by province among antenatal clinic attendees³

PROVINCE	HIV PREV (CI 95%)	HIV PREV (CI 95%)	HIV PREV (CI 95%)
	2002	2003	2004
KwaZulu-Natal	36.5 (33.8 – 39.2)	37.5 (35.2 – 39.8)	40.7 (38.8 – 42.7)
Gauteng	31.6 (29.6 – 33.6)	29.6 (27.8 – 31.5)	33.1 (31.0 – 35.3)
Mpumalanga	28.6 (25.3 – 31.8)	32.6 (28.5 – 36.6)	30.8 (27.4 – 34.2)
Free State	28.8 (26.3 – 31.2)	30.1 (26.9 – 33.3)	29.5 (26.1 – 32.9)
Eastern Cape	23.6 (21.1 – 26.1)	27.1 (24.6 – 29.7)	28.0 (25.0 – 31.0)
North West	26.2 (23.1 – 29.4)	29.9 (26.8 – 33.1)	26.7 (23.9 – 29.6)
Limpopo	15.6 (13.2 – 17.9)	17.5 (14.9 – 20.0)	19.3 (16.8 – 21.9)
Northern Cape	15.1 (11.7 – 18.6)	16.7 (11.9 – 21.5)	17.6 (13.0 – 22.2)
Western Cape	12.4 (8.8 – 15.9)	13.1 (8.5 – 17.7)	15.4 (12.5 – 18.2)
SOUTH AFRICA	26.5 (25.5 – 27.6)	27.9 (26.8 – 28.9)	29.5 (28.5 – 30.5)

While Ayisi (2005) predicts that 18 million children in sub-Saharan Africa could be orphaned by AIDS by the end of 2010, Barnett & Whiteside (2002) estimate that by 2010 nearly two million children in South Africa will be without family or support. Ramsden (2002) suggests that this number is likely to increase to 5 million in 2015.

To demonstrate the impact of the pandemic at a local level, Hlongwa (2003)⁴ estimated that ninety percent of patients attended to at King Edward VIII hospital in Durban are HIV positive. A study conducted by the Centre for AIDS Development, Research and Evaluation (2002) indicates that AIDS patients outnumber patients with other illnesses in government hospitals. The study further reports that the doctors in at least two major hospitals in Durban say that between 55% and 65% of medical in-patients are HIV positive and the vast majority present AIDS-related illnesses. Medical beds at two hospitals in Pietermaritzburg and several rural hospitals are running at 120% over capacity because of AIDS. Such figures demonstrate that the South African picture at present looks bleak. Unless major changes occur in current interventions that could significantly alter the course of the epidemic, the future is set

³ The true value is estimated to fall within the confidence limits, thus the confidence interval (CI) is important to refer to when interpreting data.

⁴ Reported in the KZN/CAPE NEWS, 9 March 2003

to get worse. It is against this background that community home-based care (CHBC) has gained centre stage. According to the National Guideline on Home-based care and Community-based care (2001:2), as more people become ill, many will not be able to stay in hospitals, hospices or other institutions for care due to limited health care resources in South Africa and elsewhere. It is envisaged that situations will arise where, even if hospital or other institutional care may be the best response to an individual's condition, it may not be available to them. The reasons for this include:

- Shortage of hospital beds
- Inadequate number of medical, nursing and allied health professionals in the public sector
- Lack of drugs and resources for treatment
- Increasing demands of curable conditions that compete with HIV AND AIDS for resources
- Crowded and over-stretched hospitals that are often unsuitable for managing patients with terminal or long-term diseases
- Cost of institutional care.

Steinberg, Johnson, Schierhout & Ndengwa (2002: iii) observes that in many African communities, infected people are already being cared for and supported by voluntary caregivers, because "the public health system is barely coping, as a result many people are sent home to die". Community home-based care (CHBC) which is care occurring at a patient's residence to supplement or replace hospital care, emerged in sub-Saharan Africa in the late 1980s and early 1990s as an immediate and direct response to the HIV and AIDS epidemic. According to Khomanani (2002), CHBC has since assumed enormous significance in Southern Africa and elsewhere as care and support service which complements formal health care to combat the impact of HIV and AIDS on development. In Uys (2003: 3), the Committee on a National Strategy for AIDS concluded that, "if the care of the sick people is to be both comprehensive and cost-effective, it must be conducted as much as possible in the community, with hospitalization only when necessary".

However, the strains on those caring for people with HIV and AIDS are enormous. Due to the high rate of unemployment and poverty in South Africa, many homes are

unable to ensure optimal quality care. In addressing this challenge, CHBC service providers and practitioners recruit, train, supervise, and support voluntary caregivers who could in turn support families in the local community (Uys, 2003).

This study seeks to explore the kind of training that is being offered to voluntary caregivers working in the field of community home-based care with a view to examining whether the training equips them adequately for the challenges encountered during home visits. It is essential to realize that the quality of care that CHBC volunteers provide and their ability to do so over a sustained period, depends on protecting their own well-being and morale. Although this is well recognized in principle, UNAIDS (2000: 5) argues that care for CHBC volunteers is rarely given the priority it deserves. It is fitting, therefore, to provide a critical curriculum analysis of CHBC, which according to Jansen & Reddy (1994: 5), “unpacks the curriculum into its component parts, evaluates how the parts fit together in terms of focus and coherence, checks underlying beliefs and assumptions, and seeks justification for curriculum choices and assumptions”. In an attempt to distinguish a “curriculum” from a “course”, Rogers (1992: 131) maintains that “methods and content together make up the curriculum”, while, Boud (2001) recognizes that the course focuses largely on the preset syllabus.

The research study was conducted with the assistance of voluntary caregivers belonging to a non-profit making AIDS organization⁵ based in Mpophomeni, a township located approximately 30km North of Pietermaritzburg. The objective of the AIDS organization as stated in their mission statement, is to reduce the incidence of AIDS pandemic⁶ and its stigma, and to equip AIDS-affected families so they can remain integral and active members of the community they call home. The staff belonging to the organization does this by strengthening the work of community-based organizations (CBOs) through the provision of resources, coordination, and providing relevant services. The organization under study operates within the boundaries of the uMngeni Municipality, which comprises 27 areas, including

⁵ The name of the AIDS organization is withheld to ensure confidentiality and anonymity of study participants.

⁶ A disease such as malaria is considered endemic if it is continuously present in a population but at low or moderate levels, while a pandemic describes epidemics of worldwide proportions, such as influenza in 1918 or HIV and AIDS today (Barfield, 1997: 150 cited in Barnett & Whiteside 2002: 25)

Mpophomeni and Howick. The study area was selected due to the rich history of the area as explained in the discussion below.

The next session locates the research study within the context of the study area. Jansen & Reddy (1994) caution that in curriculum analysis, development practitioners need to consider the external environment, which has a large influence on any educational event. In support of this view, Boud (2001) maintains that if the focus point is on the curriculum, programmes must acknowledge the context of the learner.

1.2 THE CONTEXT OF THE STUDY AREA

The Province of KwaZulu-Natal

KwaZulu-Natal occupies about 92 000 square kilometers, or one-tenth of South Africa's land surface. It is the country's third smallest Province. It has the largest population in the country of approximately 9.3 million, which is about 20% of the total population of the country. About 43% of KwaZulu-Natal's population lives in urban centers. Rural communities are strongly influenced by traditional authority structures and the communal administration of land and resources. The majority of the population is Zulu-speaking, followed by English and Afrikaans speakers. The Province is home to the Zulu monarchy, whose traditional capital is Ulundi. The province's main centers of urban growth include the port city of Durban that hosts the busiest harbour in Africa, and Richards Bay which is a large industrial area⁷.

In their continuous fight against HIV and AIDS, many people within the province have come to realize that HIV is not just a health issue, but a development one as well. Therefore, HIV and AIDS must be addressed as a development issue and not exclusively as a health problem. It is both driven by factors that are contextual – political, social and economic – and also impacts negatively on these contextual realities, deepening already existing vulnerabilities and increasing already existing socio-economic, cultural as well as political impacts.

⁷ Information is available [online] <http://www.kwazulu-natal.co.za/factfile/default.asp>

As Barnett and Whiteside (2002: 71) observe, the factors driving the epidemic include:

- Macro factors including political, social and economic factors (such as poverty and inequality, low employment rates)
- Socio economic factors such as low literacy levels, the unequal position of women in society; poor access to basic needs [such as housing and access to water]; poor access to services (including health, education and welfare); poor access to resources and information)
- Behavioral factors which include multiple sexual partners, serial monogamy, unprotected sexual intercourse, sexual mixing patterns
- Biomedical factors which include anatomy of women, transmission from mother-to-child during childbirth and breastfeeding, blood transfusion

Poverty remains the biggest threat as it compromises the efforts implemented to curb the spread of HIV and AIDS. Due to poverty and unemployment, women and girls are still vulnerable to risky sexual behaviour, including prostitution and dependency on men for financial benefits. In many of these situations, women fail to assert themselves and negotiate for safer sex through condom usage. Although male condoms are distributed for free in public clinics, schools, hospitals, toilets, etc, women still find it difficult to access the female condom, which, in contrast, is never provided for free.

The impact of poverty on the spread of HIV and AIDS is illustrated explicitly in a survey of households affected by HIV and AIDS in South Africa. The study was jointly commissioned and published by the Henry J. Kaiser Family Foundation and Health Systems Trust. In that particular study, Steinberg et al (2002) demonstrate that no sector of the population is unaffected by the HIV epidemic. However, the study further shows that it is the poorest South Africans who are most vulnerable to HIV and AIDS and for whom the consequences are inevitably most severe. The households were randomly selected from the client lists of non- governmental organizations providing support to AIDS-affected households in the regions where the survey was conducted. This study reveals a causal link between poverty, HIV and AIDS. The

women voluntary caregivers operate within the context outlined above which is characterized by poverty, unemployment, HIV and AIDS.

The next session focuses specifically on the Mpophomeni area, highlighting historical background and outlining some of the socio-economic issues in the area, a discussion that is fundamental and relevant to understanding this research.

Historical background of the study area: “Mpophomeni a community of suffering and hope”⁸

The AIDS organization under investigation falls within uMngeni Municipality that was named after the river that runs across Howick and Mpophomeni. According to the study that Kumalo (2005) conducted, Mpophomeni is named after the Howick falls. The Zulu word ‘Mpophomeni’ means waterfall. The area of Mpophomeni previously belonged to the Lund family who ran a farm from the 1890s. This farm was declared a black spot, which meant a place earmarked for black people who were moved from places close to the city centers. It also had to accommodate farm dwellers who provided labour in the surrounding farms. During the forced removals, Mr. Lund was required to relocate to another place so as to create space for black people who were being moved to his farm by the government of the day. Mr. Lund refused to leave his farm, instead he committed suicide. The first inhabitants of the new township were labourers who had arrived in 1966 for the construction of the Midmar Dam⁹. The first individual houses were built in 1968, and more houses were constructed in 1972. Eventually, the removals resulted in overcrowding in the Mpophomeni area. The available housing could not absorb all new arrivals (Bonnin, 1998). According to Kumalo (2005), the problems related to housing in the area need to be analysed within this background of the study area.

Poverty is also a reality in the Mpophomeni area as is the situation in many parts of KwaZulu-Natal. In reflecting on the BTR Sarmcol strike, a major strike in the history of South Africa, which took place in 1985, it is not difficult to identify and locate the

⁸ Kumalo (2005) used the title for a paper presented at the Conference organized for faith-based organizations with the theme ‘Broken Bodies, Healing Communities’. The Conference was held on 19 – 21 October 2005 at The Chantecler Hotel, Botha’s Hill, KwaZulu-Natal.

⁹ The dam has become a tourist attraction with its exciting surroundings that includes a game reserve and a museum.

cause of such high unemployment rate in the community of Mpophomeni. According to the Workers Solidarity Magazine (1999)¹⁰, workers from a British multinational, BTR Sarmcol embarked on a strike after dissatisfaction with their working conditions. The bosses fired all 970 strikers, members of the then Metal and Allied Workers Union, which was not recognized by plant management. Both Kumalo (2005) and the Workers Solidarity Magazine (1999) recognize that the BTR Sarmcol was the main industry in the Howick region responsible for the livelihood of many residents in Mpophomeni since 39.5% of the total workforce of Sarmcol came from Mpophomeni. Out of the 970 strikers who were dismissed, 400 were from Mpophomeni. The Sarmcol Management decided to employ cheap labour from the neighbouring rural areas. According to Bonnin (1998), the community of Mpophomeni was torn apart by the resulting conflict between strikers and the new workers hired by management to replace them. By the year 1999, 39 people had been killed in fighting related to the dismissals. During the same period, Mpophomeni was also hard-hit by the political struggle between two major political parties in KZN at the time, that is Inkatha Freedom Party (IFP) and the African National Congress (ANC). In his reflection, Kumalo (2005) observes how the Mpophomeni people have restored hope in the midst of suffering. Since the political violence in the area lasted for almost 10 years, the people of this community are still in a process of rebuilding their lives to bring about reconciliation.

Socio-economic situation

Like many regions in the different parts of South Africa, some areas of the uMngeni Municipality are marked by substantial wealth, while other people live in dire poverty. According to the statistics provided from Census (2001), an estimated 7 081 (10%) out of the total population of 73 896 have never had any form of schooling, and this could suggest a high level of illiteracy in the area. It is further reflected that an alarming proportion of 44 887 (60%) of the population do not have any form of income, while 11 536 (16%) of the population are unemployed, with 15 834 (21%) that are not economically active, and these figures could be interpreted as indicating the plight of those communities affected by poverty within the Municipality. This information demonstrates that Mpophomeni is no exception to the realities facing

¹⁰ Issue No 9 May 1999

many South Africans, given the high rate of unemployment, poverty, and HIV and AIDS in South Africa, particularly in KZN.

Despite the unavailability of official HIV and AIDS statistics, a study conducted in the Mpophomeni area by Kumalo (2005)¹¹ indicated that between 39% and 49% of the people of Mpophomeni are HIV positive¹². Kumalo (2005) further reports that people of Mpophomeni started noticing the impact of HIV and AIDS in 1997, however the situation worsened in 2003/2004 as more people became infected. About 30% of the women in the area attending antenatal clinic have tested HIV positive. In the same report, Kumalo (2005) mentions that 40% of the women who have tested HIV positive are schoolgirls between 13 and 18 yrs. This, he argues, indicates that a large number of teenage girls who are already infected have intimate relationships with older men. However, this situation is not unique to Mpophomeni, but common in the different parts of South Africa, which are poverty-stricken. For example, Lamptey, Wigley, Carr & Collymore (2002) report on similar occurrences whereby due to poverty and hunger, many young girls of school-going age are forced into dependency roles. They often exchange sex for food, school fees and clothes (Lamptey et al, 2002).

The AIDS organization in the study reported that despite the high rate of HIV infection in the area, many people are still reluctant to undertake voluntary counseling and testing (VCT), so as to know their HIV status. The reluctance could be attributed to the slow delivery of ARV rollout. Recent developments in the field of HIV and AIDS have clearly shown that prevention interventions will be more effective if they are closely linked with treatment, care, and support programmes. Until recently, both prevention and care programmes through voluntary counseling and testing proved inadequate without the treatment component. Many people were reluctant to go for HIV testing in the absence of ARVs in public hospitals. In 2003, the South African government improved its existing policies by including ARVs as a critical component of the larger comprehensive plan to care for people living with HIV and AIDS (PLWHA). The people of Mpophomeni who are living with AIDS and already have a

¹¹ Interviewed fieldworkers from two community organizations who were all in agreement with the figures.

¹² The two major hospitals, Edendale and Grey's Hospital, accessible to local people also confirmed the available statistics.

CD4 count of less than 200 are included in the ARV rollout programme, and they access their ARVs from the Howick Celimpilo Development Clinic (CDC).

Community-based organizations (CBOs) in the Mpophomeni area have risen to the challenge. It was reported during the interviews that four organizations¹³ work in the area of CHBC, particularly providing care services to the terminally ill members of the community. All organizations rely on voluntary caregivers who willingly and readily provide care services to the local families.

1.3 RATIONALE FOR THE STUDY

This research on community home-based care (CHBC) grew out of the HIV and AIDS Programme of the Diakonia Council of Churches. While working for the Diakonia Council of Churches, a faith-based organization in Durban fighting for social justice, as their AIDS Network Coordinator (2001 – 2005), I observed during workshops and other interactions with volunteer caregivers that their situations were complex. In the quest for justice, it seemed necessary and appropriate for me to spend time listening to their life stories so as to utilize learnings originating from their personal experiences to inform future community-oriented interventions.

At a personal level, I have also been affected by HIV and AIDS, just like many other South Africans who have lost either a friend or a relative to AIDS. Having lost too many friends and relatives to this pandemic, the reality of care hit home when my eldest sister suffered from an AIDS-related illness in 2002 and finally lost the battle on 30 July 2003, shortly after the death of her 6-month old daughter. This reality has been the basis for my interest in conducting such a study, and this dissertation is dedicated to her memory. Added to this painful experience, was the death of my younger sister to AIDS on 30 July 2005 while completing this study.

Inspired by my own personal experience as outlined above and also feminists' views on the need for women to develop their own voices (Hurtado, 1996), I have used the active voice in documenting issues raised in the study and intentionally chose not to make myself invisible behind the term commonly used in many research studies, that

¹³ The names of the four organizations have been withheld to ensure confidentiality and anonymity of study participants.

is, the researcher. Therefore, I will use a personal pronoun 'I' to refer to myself. This move is supported by Mouton (2001:130) who states: "nowadays it is perfectly acceptable, and even encouraged to let the author speak."

1.4 PURPOSE OF THE STUDY

The current trends of the pandemic as outlined above reflect that people living with HIV and AIDS (PLWHA) and their families will eventually rely heavily on voluntary caregivers for care and support. As already observed in some communities, the backbone of community care programmes for PLWHA are volunteer workers. Some are informal volunteers such as friends and neighbours who care for sick people they know out of a sense of love and duty. Others are people, such as church members, who charitably give time to community service. However, the vast numbers of people working for HIV and AIDS care programmes are formal volunteers, who are recruited, trained and supervised by the organizations they are associated with on an agreed basis (Uys, 2003).

In an effort to understand the long-term impact of volunteerism and reliance on voluntary caregivers working under the circumstances outlined above, this study contends that quality community home-based care to those infected and affected by HIV and AIDS, requires care for caregivers.

The main aim of this study, therefore, is to examine whether the training in CHBC equips voluntary caregivers adequately for the challenges encountered during home visits. The study further seeks to explore and describe personal experiences of women volunteers working in a CHBC setting, including their reasons for engaging in such programmes, as an important basis for designing curricula.

1.5 OBJECTIVES OF THE STUDY

The main focus of the study is to explore the content of the current CHBC training designed specifically for volunteer workers who provide care and support to PLWHA and their families, and compare this with the working reality of voluntary caregivers. This should allow me to determine the extent to which the CHBC training is sufficient

in preparing women volunteers for the challenges they will later encounter in their work practice. Specifically, the study seeks to achieve the following objectives:

- To establish the psycho-socio, economic, and cultural environment in which caregivers operate
- To ascertain what the CHBC training programme (content) entails and if it appropriately addresses the challenges imposed by HIV and AIDS
- To assess if the CHBC training utilizes the wealth of experiences the community caregivers bring into the learning process
- To find out the extent to which the CHBC training programmes adequately prepare participants to deal with their own life situations and face the challenges of their work as community caregivers

The information gained from this study could be used to:

- Formulate recommendations for intervention by the different civil society organizations, particularly organizations that are HIV/AIDS-focused such as the organization under study, and generalist organizations that focus on lobbying and advocacy such as the Treatment Action Campaign
- Highlight the needs of voluntary caregivers in CHBC programmes, so that these needs are reflected in policy and practice of CHBC
- Provide a resource for CHBC providers and other groups of women to reflect on the importance of self-awareness
- Design the content of the current CHBC training provision so that it effectively responds to the needs of voluntary caregivers while taking into account the needs of PLWHA and their families
- Highlight the need for systematic and coordinated care and support for those who care for PLWHA and their families

1.6 THEORETICAL FRAMEWORK

Feminist critiques on community care

The study is primarily influenced by the feminist critiques of community care. The popular notion links community and care, that is, it sees communities as both the major and the best source of care for people with long-term illnesses. Williams (1997) notes, however, that it is mainly, though not entirely, women who form the

focus for the dynamics of care and support. In her analysis, she further observes how women figure disproportionately amongst poor people. When looking at the major groups who experience poverty in the community, Williams (1997) asserts that women are over-represented. It is therefore worth noting that while presented by policy-makers as a way of supporting the social independence of those receiving care, feminists recast community care as a policy that reinforces the economic dependence of women. A sizeable feminist literature on caring provides a critical commentary on community care, highlighting the way in which both the ideology and the practice of community care rests on, and reinforces gender divisions.

The feminist literature forms a major part of the theoretical framework of this study and therefore will be explored further in chapter 2.

Paulo Freire on critical consciousness

The study is also influenced by Paulo Freire's approach on critical consciousness. The Freirean approach encourages a closer look at the structure of social and economic relationships within society. It maintains that when you raise people's consciousness they will be able to identify their own needs and in turn challenge the material reality. The approach recognizes that education can lead to self-enlightenment and increased self-understanding of groups in society. The more people know about conditions of their own action and about the overall workings of their society, the more they are likely to be able to influence the circumstances of their own lives (Burkey, 1998). It is against this background that Freire's critical consciousness looks at providing poor communities with access to better opportunities by challenging the root causes of social ills such as poverty. For, it is strong well-informed communities that are most effective in achieving constructive change.

Freire's work with the poor illiterate of Brazil helped him to realize that the banking method of education, which emphasizes passive listening and acceptance of facts, kept his students disempowered (Freire, 1970). Believing that education was for the purpose of liberation, Freire had students discuss and reflect on relevant life issues such as the inadequate pay they received as rural workers. Through this process, workers recognized the larger societal structures that oppressed them, and how they

could overcome these barriers. Through consciousness-raising, or “conscientization”, learners came to see the world and their place in it differently. Empowered in their new perspective, they could act to transform their world (Freire, 1970: 27).

The Freirean approach is relevant to this study in the sense that it takes a closer look at the teaching methodology in order to ascertain whether the primary aim is to “liberate or domesticate” learners (Freire, 1971 cited in Shor, 1993: 25). Likewise, the training in CHBC shall be examined in that similar manner in the final analysis.

1.7 ASSUMPTIONS UNDERLYING THE STUDY

This study is based on the assumption that the CHBC training curriculum for voluntary caregivers considers care primarily a technical skill and therefore focuses mainly on vocational training. As a result, it fails to take into account the aspect that the practice of CHBC involves emotional, social, and spiritual dimensions. My own assumption is that there is a wide gap between theory and practice in the field of CHBC, that is, the content of the CHBC training does not match the needs of voluntary caregivers on the ground.

1.8 LIMITATIONS OF THE STUDY

There are a few limitations to the study, and these are discussed in detail in chapter 3. The discussion entails measures taken to overcome the challenges encountered. The challenges are as follows:

- Lack of access to beneficiaries of CHBC in the home
- Distance and accessibility
- Lack of access to major CHBC organizations
- Inability to complete the study within the given timeframe

1.9 ORGANIZATION OF THE THESIS

This chapter introduces the reader to the aims and objectives of the study, hence it provides a justification for undertaking this particular study. The study takes provides a historical background of the area of Mpophomeni, thus giving a context in which caregivers operate. The loss of my two sisters to AIDS and my own involvement in

HIV and AIDS-related issues, are mentioned as my motivation to undertake this study.

Chapter two presents the definition of concepts and the theoretical framework used in the study. It also looks at the content of a CHBC training course, by highlighting the information that emerged from the documentary review of training manuals. This chapter also highlights the context in which caregivers operate and also demonstrates the needs of both the caregivers and the beneficiaries of care. It finally looks at the need for situated learning, and concludes with the needs of PLWHAs and their families.

Chapter three gives a detailed examination of the methodology used in the research process, and also provides a justification for the chosen design. This study uses a qualitative design, and the sample size consisted of 10 voluntary caregivers from the area of Mpophomeni. Observation, semi-structured interviews, and documentary analysis were used in data collection.

Chapter four focuses on a detailed presentation of the findings. This chapter, having being separated from the analysis chapter five, affirms the voices of the women by focusing solely on what they had to say. The 10 voluntary caregivers interviewed in the study describe what their context of work looks like. The course content illustrated what the CHBC training entails. Thereafter, the chapter highlights the needs of voluntary caregivers. In so doing, it concludes by demonstrating a gap between theory and work practice.

Chapter five presents the analysis and discussion of the findings. This chapter challenges the underlying principles in community home-based care (CHBC). The analysis of the profiles of women interviewed indicates how poor people help other poor people, while working for free. The analysis further demonstrates how caregiving is perceived as invisible labour since it has not really achieved the recognition it deserves in the public domain.

Chapter six draws out conclusions and recommendations to be disseminated to CHBC service providers, and other relevant stakeholders. It also involves suggestions for

further research to be conducted in the area of CHBC. Moreover, it calls for a critical consciousness needed to transform the lives of women caregivers.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The primary aim of this chapter is to explore literature in the field of community home-based care (CHBC) in order to ascertain what has already been written on the topic of this study. The literature review conducted revealed that while much research work has been done in the area of community home-based care, there was little evidence of research focusing on the CHBC curriculum and the specific needs of caregivers. Therefore, it is hoped that this study will contribute significantly to existing literature in CHBC as it specifically seeks to address the training needs of voluntary caregivers, who eventually provide home care services. Ultimately, it is hoped that the study will contribute to the improvement of the existing CHBC curricula. The main reason for choosing to analyse the curriculum is “to examine whether assumptions underlying the CHBC curriculum are valid and defensible” (Jansen & Reddy, 1994: 5), that is, whether voluntary caregivers need to learn vocational skills in CHBC, which consists of mainly practical basic nursing skills.

During the literature search, I discovered that there is a lack of research linking training and community home-care services. Both local and international literature only provide a broad overview of the concept of CHBC. While Uys (2003) rightfully validates the significance of CHBC and also manages to provide a comprehensive outline of a CHBC framework which includes a training content, her analysis is limited in that it fails to present an objective discussion aimed to demonstrate CHBC’s usefulness and effectiveness in under-resourced contexts. However, the studies conducted by Akintola (2004), Harber (1998), Nkwe-Mabua (2000) contribute significantly to close the gap as they argue explicitly on the need to revisit the policies on community care. Again, Akintola’s (2004) analysis concurs with those of Barnett and Whiteside (2002) who further question the government’s economic policies on social services including health care and the reliance on voluntary caregivers.

Having outlined the aim of the study in the previous chapter, this chapter begins by providing definitions of concepts that form a major part of this study, and then outlines in detail the theoretical framework of the study, including theoretical debates around community home-based care. I then look at the context and content of different available models of CHBC. The discussion on the context highlights the different models of care and a place for situated learning in CHBC, while the content of CHBC takes a closer view at the issues of training, teaching, learning and knowledge acquisition in CHBC. Finally, the chapter offers a reflection on the factors that could contribute towards a holistic approach to the training of voluntary caregivers in CHBC.

The following concepts and their usage are to be understood in the context of this study: adult education, curriculum analysis, community home-based care, a caregiver, and a volunteer.

2.2 DEFINITION OF CONCEPTS

Adult education

This study is significantly influenced by adult education principles¹⁴. It has been well accepted within the field of adult education that attempts in the past to provide a universally acceptable definition of adult education have failed. Darkenwald and Merriam (1982: 8) state that some definitions are based on certain assumptions and value judgments that are not acceptable for everyone. As a result, there is no prescribed or universal definition of adult education. The definition of adult education, which was adopted in the UNESCO conference held in Nairobi in 1976, has been used for the purposes of this study. According to this definition, the term adult education denotes:

The entire body of organized educational processes: whatever the content, level, and method, whether formal or otherwise, whether they prolong or replace initial education in schools, colleges, and universities as well as in apprenticeship, whereby persons regarded as adults by the society to which they belong develop their abilities, enrich their knowledge, improve their technical or professional qualifications, or turn them in a new direction and

¹⁴ See discussion below: Paulo Freire on Critical Consciousness

bring about changes in their attitudes or behaviour in the two-fold perspective of full personal development and participation in balanced and independent social, economic, and cultural development (National Education Policy Investigation (NEPI), 1993: 4).

When analyzing this definition, it is evident that the scope of adult education is very wide. It goes far beyond giving lessons on reading and writing to illiterate adults. When analysed in this context, adult education is concerned with community education which is designed specifically for a particular community to meet the expressed needs and interests of that community and can be directed towards improving the quality of life. This stresses that all education should originate in and be designed to meet the interests of adult learners¹⁵ in the community. In the context of the CHBC training under investigation, the content of the training as outlined in the training manual also includes a session on the teaching of adults. It will therefore be interesting to see later in chapter 4 how this is put into practice.

Curriculum analysis

Jansen & Reddy (1994: 4) acknowledge the difficulty to define this concept, which “actually means different things to different people”. However, they recognize that while curriculum development involves building the curriculum in order to present a coherent plan, curriculum analysis on the other hand, involves unpacking the curriculum in order to understand the plan. In his analysis, Boud (2001), argues that an emerging curriculum has to be driven by the context and demands of new knowledge.

Authors such as Rogers (1992: 31) recognize that even in the field of adult education, there is very little written on the topic of curriculum, instead “most of the work on curriculum has been done in relation to schools”. To overcome the challenge, Rogers (2002) realizes the necessity to adapt what is available on school curriculum to adult education. My literature on curriculum relied heavily on the work of Boud (2001: 45) in his contribution on work-based curriculum. While his literature on curriculum

¹⁵ In the context of this study, the concept of ‘adult learner’ is used to refer to ‘CHBC voluntary caregivers’.

focuses on the workplace, the insights are relevant to the current study because he acknowledges that learners do not learn in a vacuum, but they have “a context in a particular setting at a particular time with various demands placed on them”. The significance of this argument is that women voluntary caregivers generally bring a particular context to the learning situation in the many roles and responsibilities that they need to fulfill within and outside the home. It is on that premise that Jansen & Reddy (1994) maintain that there should be a story behind the curriculum that needs to be understood within the historical context.

If the study primarily aims to analyse the CHBC curriculum, I also need to consider the teaching process. According to Boud, Cohen & Walker (1993), it is usually advisable for educators of adults to adopt approaches that allow and create space for learners to explore, experience, imagine, and invent their own knowledge by building on their prior knowledge. Many authors encourage a teaching process to be learner-centred, as opposed to teacher-centred (Freire, 1993). However, some authors advocate for a learner-teacher-centred approach (Baumgartner, 2001), for they recognize and acknowledge the contribution of both the teacher and learner into a learning situation. According to this view, as much as it is critical for educators to facilitate learning as opposed to imposing their own worldview, there is still a need for new information to be disseminated. I also support the latter view which encourages a learner-teacher-centred approach, whereby both teacher and learner come to the learning situation as equals, ready to share information and knowledge and in the process of teaching and learning, both having opportunities to learn from each other.

In identifying key learning themes, Boud (2001), Daines & Graham (1988) focus on prior learning that the learner brings to the programme. Daines & Graham (1988) maintain that learners engage in a process of reviewing what they have learned from their experience and how this relates to what they desire to learn. In so doing, new learning undertaken is able to build on existing knowledge.

According to Rogers (1992: 142), there is a basic range of teaching methods and these methods could be divided into three main categories:

- Presentation methods, which are teacher activities such as demonstration, lecture, exposition, use of a flipchart, text or audio-visual media.
- Interaction methods between educator and learner, or learner and learner, such as questions, role-play, discussion, buzz groups.
- Exploratory methods in which the learners on their own or in groups work on tasks, such as practice, experiments, reading, writing.

Dirkx (2001) also adds the imaginal method which is concerned with uses of images to understand deeper feelings and emotions in adult learning. The methods include journal writing, literature, poetry, art, movies, story telling, dance, and ritual to encourage learners to share intimate issues related to emotions and feelings. In chapter 4, the study explores the different methods used in the CHBC training that I observed, and the relevance of the learning that takes place.

Community home-based care

Many authors such as van Dyk (2001) & Uys (2003) define community home-based care (CHBC) as care occurring at a patient's residence (community care) to supplement or replace hospital care (institutional care). Care at home, according to Sims & Moss (1991) involves caring for the patient and those important to him/her as a unit. When it is successful, care provided in the familiar surroundings of the home, with multi-professional input from statutory and voluntary services, can produce the very best of terminal care. Sims & Moss (1991) further argue that in the freedom of their own homes, people's independence is often more easily maintained and they can behave as they wish.

In support of this approach to care, the government's operational plan (2003) affirms the link between the primary health care facility and community home-based services as central to achieving good patient follow-up and continuity of care. It is evident from this definition that at best, community home-based care links both the family and community to the available health care services.

Having mentioned the place and role of community home care, there is yet a need to critically reflect on the benefits of such care. The concept of community home-based care is at the very core of this study for the study asks questions related to the voluntary caregivers' needs, including the following: Could 24 hour care be provided when it is needed? Who will give the tremendous input of skilled counseling needed by these patients and those they love? Is it realistic to expect bereavement support and follow-up to be provided to families at home? Voluntary caregivers in many communities fulfil these roles and many others.

A caregiver

There are different types of caregivers within the context of CHBC. According to Miller (2000), primary caregivers are normally informal¹⁶ carers, including family members and friends, and secondary caregivers could be either the community voluntary caregivers or community health workers¹⁷ who are normally paid by the government or employed by hospices. This study's interest is on voluntary caregivers who are community home-based volunteers who are recruited, trained and supervised by organizations that they serve.

Caregiving, according to the Operational Plan (2003) within the context of community home-based care has to ensure a "continuum of care"¹⁸, that is, a swift transition from a positive HIV test result to treatment and care. Sims & Moss (1991: 19) recognize the particular role of this continuum care, which is to offer a multi-professional team to provide a holistic approach to care for the individual. Ideally, the core of the team should include nurses, a doctor, therapists, a dietician, social workers, counsellors and psychologists, and chaplains and ministers of religion, either to give regular in-put or to be available when needed or wanted. In this continuum of care, a voluntary caregiver is also seen as a key role player.

¹⁶ See informal home-based care below

¹⁷ See community health workers home visit below

¹⁸ Components of this continuum of care include prevention-related interventions; voluntary counseling and testing (VCT); medical care and treatment by a dedicated; trained medical team; psychological support; nutritional assistance; social supports; community-based services and home-based care as needed (Operational Plan, 2003)

A volunteer

The literature search on a definition of volunteer provides a wide variety of meanings. It needs to be stated that the concept of volunteerism is not clearly defined in the government health policy. Ramafoko (2005) supports this view in saying that the term 'volunteer' is not adequately defined. Section 83 A (1) of the Basic Conditions of Employment Act (2002)¹⁹ clearly states that "a person who works for, or renders services to, any other person is presumed to be an employee, regardless of the form of contract". If this definition were adhered to, it would place CHBC caregivers under the banner of employees and that they should be getting a financial reward for their services.

In an attempt to define a volunteer, I have chosen to use the definition of Smith (1989 cited in Merrill, 2000) who defines volunteers as individuals who reach out beyond the confines of their paid employment and of their normal responsibilities to contribute time and service to a not-for-profit cause in the belief that activity is as beneficial to others as satisfying to themselves. Merrill (2000) recognizes that despite the varied and contrasting definitions of volunteerism, a unifying concept is the idea that volunteers are not paid. Seen in this way, volunteerism, according to Merrill (2000), is conducted without primary or immediate thought of financial gain.

The year 2001 was the International Year of the Volunteer, but the term 'volunteer' had not been fully understood within the South African context, particularly in the field of community home-based care. At a Conference²⁰ held the following year, President Thabo Mbeki (2002)²¹ declared the national year of volunteers and also launched the "letsema"²² programme". Speaking at that Conference, the United Nations Development Programme (UNDP) Deputy Representative, Naheed Haque, mentioned that the spirit of volunteerism already exists in South Africa in the area of HIV and AIDS. Surprisingly, she further stated that the work of volunteers adds to

¹⁹ Department of Labour. The Basic Conditions of Employment Act, No 11 of 2002. available [online] www.labour.gov.za/download/7881/Amended

²⁰ A two-day Regional Volunteer Vision Conference held on 16 – 17 May 2002 in Midrand, South Africa. Approximately 250 participants from eight Southern African Development Community (SADC) countries gathered to explore ways of volunteerism.

²¹ Available [online] at: <http://www.info.gov.za/speeches/2002/02050916111002.htm>

²² A Sotho word meaning "volunteerism". The Letsema programme aimed to encourage individual South Africans to contribute to the socio-economic development of the country through volunteer action.

the calculation of gross domestic product by citing a study conducted by the School of Public Administration of the University of Witwatersrand which found that volunteers represent 43% of the work in the non-profit sector, with a contribution of 5.1 billion rands to the national output.

The tendency to put too much emphasis on the cost-effectiveness of volunteerism overlooks the hard cost²³ on those who provide such care. The failure on the part of political officials to recognize the difficulties related to volunteerism in resource-constrained environments has been highlighted by civil society organizations such as COSATU (Makgetla, 2002). Government documents such as the National Guidelines on Community and Home Based Care (2001) overtly acknowledge the role of volunteers in providing care as a cost-effective exercise, however, studies such as that conducted by Akintola (2005) have shown that a large number of women caregivers are living in dire poverty. As reflected in Chapter 1, women voluntary caregivers working in the Mpophomeni area are no exception.

Loewenson & Whiteside (1998) also demonstrate that home-based care has been found to be costly in rural areas: costs in time, supplies, transport and patient care are often unaffordable for poor families. The belief that the extended family is capable of taking such responsibility of care, according to Barnett & Whiteside (2002: 187) relieves politicians of the responsibility of thinking through the implications of the epidemic. They warn that the extended family reaches a point where it can no longer cope. These views are supported in a study conducted by Rugalema (1999 cited in Barnett & Whiteside (2002) which shows how coping mechanisms become increasingly weakened as more households in a community are affected and communal support networks are less and less able to cope.

The next section presents the theoretical framework that informs the study, including the outline of the key arguments amongst the proponents of community care and those who are against such approaches. Such theoretical debates are fundamental for the purpose of this particular study in relation to locating the historical context of community care, challenges, and strengths of this approach to care.

²³ In this context, "the hard cost" should not only be understood in financial terms, but should also include among other things time and energy.

2.3 THEORETICAL FRAMEWORK

Paulo Freire on critical consciousness

As a Professor at the University of Recife in the early 1960's, Freire worked with peasants in the Brazilian Northeast during the country's national literacy campaign (McLaren & Leonard, 1993). At this time, he evolved a theory based on the conviction that every human being is capable of critically engaging the world in a dialogical encounter with others. According to Aronowitz (1993: 15) "any learning that is aimed at helping learners engage in a dialogue seems crucially directed to breaking the cycle of psychological oppression as it helps learners to confront their own lives". In a Freirean classroom, the main purpose would be to enable learners to articulate their own feelings. It is against this background that Freire (1993) encourages educators to always tie their narratives of liberation to people's stories.

Freire's analysis indicates that teaching and learning are human experiences with profound social consequences. "Education is not reducible to a mechanical method of instruction" (Shor, 1993: 25). Instead of transferring facts and skills from educator to learners, a Freirean class invites learners to think critically about subject matter, the learning process itself, and their society. Freire's social pedagogy defines education as one place where the individual and society are constructed, a social action which can either empower or domesticate students. In a 'liberating classroom', Freire's educators pose problems derived from a learner's life and social context, in a mutually created dialogue. Shor (1993) argues, therefore, that in Freirean critical environments, educators reject the methods that make learners passive and anti-intellectual. Instead, the Freirean critical education invites students to question the system they live in and the knowledge being offered to them, to discuss what kind of future they want.

In situations where dialogue is absent, Freire (1970: 58 cited in Shor, 1993: 26) maintains that, "a banking education" is promoted whereby the learners are treated like "empty vessels" in which information could be deposited. Daines & Graham (1988) note that banking education is against the principles of adult education. Adult education principles are based on an assumption that adult learners bring their own experience into the learning situation, and that this provides a foundation for them to build upon. In a dialogue with learners, educators are able to facilitate learning,

which has personal meaning and relevance. Boud, Cohen & Walker (1993) support these views by maintaining that adult learners will learn new knowledge, attitudes or skills best in relation to life experience. Daines & Graham (1988) further argue that such significant learning is likely to be more readily acquired than that which has little use or importance to individuals or to their lives.

When education is seen in this way, the kind of education that Freire advocates helps learners to recognize the larger societal structures that oppress them, and how they could overcome these barriers. According to Baumgartner (2001), “through consciousness-raising, or conscientization, learners come to see the world and their place in it differently”. Having being empowered in their new perspective, the ultimate aim for this kind of education is for the learners to transform society.

Having said all this, I fully recognize the limitations and the criticisms leveled at Paulo Freire’s theory. One criticism being that Freire tended to address only the oppression that was based on class but omitted oppression based on gender, race, ethnicity, and language (Archer & Cottingham: 1995). Nevertheless, I still find his theory relevant for the purposes of my study, particularly in analyzing whether the teaching approaches used help learners to become critical thinkers, or are the approaches geared towards domesticating the learners to obey and respond to the needs of the government officials, policy makers, and researchers while overlooking their own needs.

Feminist perspectives

I need to mention from the outset that it is not the intention and focus of this study to engage in the debates that exist between the feminists and the womanists. This particular study aims to discuss broadly the issues that affect women from all walks of life. I therefore will pay no particular attention to the women of colour’s critique of white feminist theory that it does not represent the experiences and perspectives of members of society who are marginalized by race or class. The following discussion looks at the feminist perspectives under three broad categories deemed relevant for the purposes of this study: The personal is political, feminists’ views on the production of knowledge, and women as collective agents of structural change.

The personal is political

According to Hooyman & Gonyea (1995), what happens within the home is not exempt from the political forces that affect the rest of society. The notion that the personal is political identifies and rejects the public versus private dichotomy by which women are excluded from public participation (Hurtado, 1996). The ideology of separate spheres, or the romantic solution, created the duality of a loving home and the impersonal public domain. In the context of caregiving, Abel (1986 cited in Hooyman & Gonyea, 1995) notes that as is reflected in instances of caregiver neglect or abuse, caregiving can reflect fear and obligation as well as concern and affection. Williams (1997) argues that although caring involves an intensely personal relationship between individuals, it cannot be examined apart from the public policies surrounding it. The personal is political: women's experiences as caregivers are shaped by their interactions with the public social service, health, long-term care systems and policies. She further argues that within a feminist framework, the goal is to break down the dichotomies of public versus private and impersonal workplace versus loving home and to challenge the gendered division of labour in all its forms.

Feminists' views on the production of knowledge

Part of the reason I chose the feminist framework for this study is that feminists' views on the production of knowledge are concerned with individual women developing their own voices (Hurtado, 1996). Similarly, among the objectives of the study, one is concerned with ascertaining how the CHBC training assists women voluntary caregivers to explore their own feelings.

In her work with women-based community organisations, Belenky (1996) is drawn to the notion of communal construction of knowledge as it relates to how community organizations working with women transform their members and the way they define truth and authority. She further describes those communities, which according to her are dialogue-rich, on how they act as a breeding ground for political commitments and activism among their members. Such community-based organizations are likely to raise all the contradictions in society, which according to Hurtado (1996) would include the politics on the production of knowledge. He asserts that not all social groups are valued equally and not all groups are allocated the same amount of

material resources, like education, jobs, and choices for determining one's life. He concludes, therefore, that the difference in value attached to significant group memberships to a large extent determines what access individuals have to knowledge, what is considered knowledge, and ultimately how it is that one comes to perceive oneself as knowledgeable in spite of one's group membership. This basic information is critical for chapter 5, as it will later show whether voluntary caregivers have access to resources and knowledge or not.

Women as collective agents of structural change

Hooyman & Gonyea (1995) maintain that giving voice to collective concerns is a first step toward changing gender inequities in care responsibilities. For individual experiences of stress to be transformed into publicly expressed claims for change, it is necessary that people talk about and share their difficulties and develop a sense of collective consciousness and identity (Baines et al, 1991 cited in Hooyman & Gonyea, 1995). As long as women continue to accept caregiving as their individual responsibility and see the existing gender inequalities in caring as natural, their privately experienced strains are not moved into the public realm and given public voice and visibility. As long as caring remains isolated and viewed as a private responsibility, most women will continue to bear the burden in silence and not see the political aspects of their situation.

Both Tallis & Cavanagh (2004) recognize that a feminist perspective is oriented toward structural change that will challenge a status quo that systematically disadvantages women and will accord greater recognition to the work of caregiving. Therefore, they maintain that transforming society should be the goal. In their analysis, transformation includes radical and fundamental change at the personal, relationship, community and societal levels as well as addressing the systems, mechanisms, policies, and practices that needed to support such genuine change. In this view of women as agents of change rather than passive victims of circumstances, Hooyman & Gonyea (1995) recognize that women cannot just be objects of public policy. Strategies for organizing for structural change must recognize the interaction between personal and political change.

2.4 AN OVERVIEW OF THE DEBATE IN COMMUNITY CARE

Institutional care versus community care

Pilgrim (1998: 168 cited in Harber 1998) notes that the idea of community care began in Europe in reaction to the policy of separation and segregation of the poor and the mentally ill. Segregation began in the 19th Century and was still prevalent in European countries in the first part of the 20th Century. Community care was developed further after the Second World War and in the 1970's the ideal community care had become a central principle on social policy in many European countries. The vision of these theories was that of a world where beneficiaries of care stayed in their homes in the community rather than in institutions and the care they had was decided solely by their needs.

In this context Barnett & Whiteside (2002) argue clearly and powerfully that the idea of community care was originally the de-institutionalization of care, but still to be provided by the state. However, in many countries today, including South Africa, community care is seen as a major means of reducing public expenditure on social services including the provision of health services. There is a dramatic shift in terms of service delivery at community-level, in the sense that the burden has fallen on communities, and most often the responsibility is carried by unpaid women caregivers in the area of HIV and AIDS. Many governments have realized that the burden of care could not possibly be their responsibility, and have placed a lot of emphasis on community care.

Uys (2003) and Ngubo (1995) acknowledge that the health system cannot cope with the load, so care at home is perceived as the most sensible option. In a similar situation, the former KZN MEC for Health, Dr. Zweli Mkhize (Leeman, 2003) highlighted the need for volunteers to provide support, particularly in the area of community home-based care, emphasizing that government programmes will not prevail without the support of volunteer caregivers. This is in accordance with the goals and objectives outlined in the National Guideline in CHBC (2001: 8), which aims "to shift the emphasis of care to the beneficiaries - the community". But, this solicits the question who or what is the 'community'? Who will provide for the care of such individuals? Is there any support available to those who provide such care?

Who benefits and who loses from such arrangements? These questions and many others will be discussed in chapter 5.

A disturbing factor is that the concept of care by the community is not often clearly defined, and as a result the provision of care becomes a burden on the family in general and women in particular. Barnett & Whiteside (2002) recognize that community care is a word of great comfort, but only for those who seek easy solutions, and Burkey (1998) warns against the tendency to romanticize community life as a place where people live together in harmony and always readily and willingly help one another.

The involvement of women in community care

In her analysis, Harber (1998) recognizes that the idea of community care is linked to, but differs from, that of community development. While both are community-based strategies, community development aims to improve socio-economic conditions in a community, through the involvement of community members in capacity building ventures. Community care, in contrast, refers to community participation in the provision of care to vulnerable members through community-based rather than institutional services. She further argues that even though certain aspects of community care may involve an element of community development, they are not contingent upon it.

Based upon this argument, the feminist critique of community care also challenges the popular notion of linking community and care, that is, seeing communities as both the major and the best source of care for people with long-term illnesses. Williams (1997) recognizes that it is mainly, though not entirely, women who form the focus for the dynamics of care and support. It is against this background that a sizeable feminist literature critiques community care, highlighting the way in which both the ideology and the practice of community care rests on, and reinforces gender divisions. Reflecting on the emerging issues, I observed that state community care policies often represent this restricted sense of community in the way they assume that it is the responsibility of women to provide unpaid care in the community. If perceived in this

way, the feminist critique of CHBC is that it is a cheap alternative source of care and support.

Currently, the Joint Civil Society Monitoring Forum (JCSMF) (2005)²⁴, which is a coalition of NGOs whose sole mandate is to monitor the rollout of the ARV programme continues to challenge government on the slow delivery of ARVs as the burden of care weighs heavily on women. Through monitoring and evaluation of government programmes, the Treatment Action Campaign (TAC) has observed that the government has failed to meet the treatment targets of the Operational Plan for Comprehensive HIV and AIDS Care, Management, and Treatment for South Africa (2003)²⁵.

The plan is committed to treating approximately 50,000 people by end of March 2004, an additional 135,000 people by end of March 2005 and another 215,000 people by March 2006 (Operational Plan, 2003: 52). Instead, the Department of Health reported at the end of March 2005 that only about 42,000 people were on treatment in the public sector. It is estimated that another 60,000 people are being treated in the private sector (TAC, 2005). If government had met its target, there almost would be 200,000 people on treatment already in 2005, and about 380,000 people would be on treatment by March 2006. The government having failed to meet these targets, the TAC recently launched a campaign to demand that the government treats 200, 000 people by 2006, including 20,000 children infected by AIDS.

In an attempt to provide the context of care, together with the training needs of caregivers, the next session looks closely at the different available models of CHBC care, and some major training manuals. The discussion further focuses on the need for situated learning in CHBC.

²⁴ Reports available from the AIDS Law Project website at: <http://www.alp.org.za>

²⁵ TAC Newsletter available [online] at: www.tac.org.za

2.5 THE CONTENT OF A CHBC TRAINING PROGRAMME

Documentary review of four CHBC training manuals

Cameron (2003: 37) cautions that a training course needs to provide training in a wide range of knowledge and skills that caregivers will need in order to provide a high standard of holistic care and support. Adult education principles suggest that adult “learning potential requires new material to be relevant, meaningful, interesting and useful” (Daines & Graham, 1988: 2). Learning for learning’s sake does not have a high priority for many people. Therefore, there needs to be recognition that a course content would need to combine theory and practice and to make provision for formative evaluation, reflective learning, and self-evaluation. Otherwise, inadequate training will result in poor care provision. Training manuals reviewed for the purpose of this study were from four different CHBC organizations.

I wanted to investigate what is offered in such trainings by taking a closer look at the content of each CHBC training package, including the duration of such trainings. Having reviewed the different manuals, it was clear that the training in CHBC does not provide a standardized format. The content and duration of the courses vary considerably. For example, while one CHBC organization provides a training course similar to the one provided by the CHBC organization under study, the length of training in the former is precisely two-weeks, while the latter spends only a week.

Generally, the average CHBC training course comprises of the following key elements:

- Overview of the role of community home-based caregivers
- Sexually Transmitted Diseases (STDs)
- Tuberculosis (TB) in the context of HIV and AIDS, HIV and AIDS in context, caring for someone living with HIV and AIDS, death and dying
- Basic nursing skills, palliative care, pain and symptom control, psychosocial and spiritual support, helping the patient with his or her feelings
- The body anatomy, nutrition, feeding
- Basic communication, presentation skills.
- Paeditriatic issues and family care
- Caring for the caregiver

- Toilet care, environmental hygiene and bed-making,
- Dressing and undressing, personal hygiene
- Wound care, administering medicine
- Caring for patients with infectious diseases

Two of the training course outlines have additional training units such as the following:

- The body and how it works, breathing
- Caring for a sick baby or child
- The caregiver and the community, the caregiver and the patient.

Comparisons between the training content of the different CHBC organizations, show that the content focuses on vocational training, that is, practical nursing care. At a glance, one of the four CHBC training organizations provides a course that is exceptional compared to the other three. The training incorporates antiretroviral therapy, six-months community practical training before certification, monitoring and evaluation of community programmes through the use of local supervisors. The key role of the rest of the organisations reflected above is to provide CHBC training services. There are no follow-up strategies in place to monitor the impact of the training at community level.

Having outlined the course content, it is fitting to analyse the context in which the voluntary caregivers operate. This is the most fundamental part of this research, as it affords me the opportunity later in chapter 5 to critically analyse the training content as outlined above and find out if it matches the needs of the voluntary caregivers.

2.6 THE CONTEXT OF CARE

In the National Guideline on Community Home Based Care (2001: 8), the National Department of Health outlines the goals and objectives of CHBC to include the following:

- Shifting the emphasis of care to the beneficiaries - the community
- Ensuring access to care and follow-up through a functional referral system

- Integrating a comprehensive care plan into the informal, non-informal and formal health system
- Empowering the family/community to take care of their own health
- Empowering the client, the carer(s) and the community through appropriate targeted education and training
- Reducing unnecessary visits and admissions to health facilities
- Eliminating duplication of activities and enhance cost-effective planning and delivering of services

Considering the need to empower the family, community, client (PLWHA), and the caregivers as outlined in the goals and objectives of CHBC, it is relevant to unpack the term empowerment. In their analysis, Tallis & Cavanagh (2004) assert that empowerment approaches address issues of access to information, skills, resources, services and technologies, and participation in decision-making at all levels. They recognise that the term empowerment is an overused word and appears to be losing its meaning. They therefore challenge the claim of organizations that insist that they empower women when women in the work of such organizations have no access to power. As it will be shown later in chapters 4 & 5, women voluntary caregivers operate in contexts characterised by poverty, hunger and lack of access to professional services. Therefore, it will be good to observe whether CHBC empowers caregivers as it has been claimed.

Basic needs of CHBC beneficiaries of care

According to Wilkes (1980 cited in Sims & Moss, 1991) the main aims of those providing terminal care should be to improve the quality of daily life by removing or alleviating unpleasant symptoms and helping to prevent the patient from suffering fear and loneliness. Consequently, both Uys (2003) and Sims & Moss (1991) maintain that those who care for people living with HIV and AIDS (PLWHA) should respond to the patient's physical needs, emotional needs, social needs, and spiritual needs.

Physical needs

St. John Ambulance CHBC Manual (2003) acknowledges that looking after someone with HIV and AIDS is hard work. People can probably take care of themselves while

they are still HIV positive, but as the disease becomes AIDS, a person requires more and more help. The physical care of PLWHA presents great challenges to caregivers. The problems commonly encountered are: fever, thrush, confusion, diarrhoea, nausea, vomiting, stomach pains, headaches, breathing problems, skin sores, sticky eyes or trouble seeing. The St. John Ambulance CHBC Manual (2003) recognizes that because HIV attacks the immune system, much of the caregiver's role will be about trying to help the PLWHA's immune system stay strong as possible. This could be done by making sure that the PLWHA eats well, and does not come into contact with diseases.

Emotional needs

Both Uys (2003) and Sims & Moss (1991) observe that the emotional environment is created by people interacting with the patient, people demonstrating that they care and showing unconditional love and acceptance. The needs for love, acceptance and security are particularly important in this care setting as many people with AIDS will have experienced rejection for much of their lives. With the diagnosis of AIDS people may experience many losses: loss of control; loss of dignity; loss of body image; loss of future; and an anticipated loss of any and everything that is important to them. Rejection, isolation and guilt may compound the feeling the person is useless, hence their self-esteem is lost. Fears may be expressed, fear of dying, of the process and of what happens after death. It is for this reason that Sims & Moss (1991: 12) advise that in responding to a PLWHA's emotional needs, caregivers need to maintain hope, honesty, be able to raise difficult and painful issues, offer encouragement and motivation, add value to the PLWHA's life, be available to listen and hold hands.

Social needs

It is observed that the lack of suitable housing is a very big problem for the person with AIDS who:

- Is homeless
- Is unable to live alone
- Lives alone but needs help
- Can no longer climb flights of stairs and needs ground floor accommodation.

- For the sick mother and her baby in bed-sit accommodation.

While dealing with these situations, one also needs to ask: is home care really an option for those people with AIDS who are living alone? For those living alone and housebound: a considerable amount of assistance with shopping, cleaning and food preparation may be needed from volunteers. A mother with AIDS may need help in caring for her baby.

Sims & Moss (1991) recognize that PLWHA also need financial help. Many PLWHA may also have fears and anxieties for the future of their partner and family, especially if they have been the main provider of income or they are a single parent. Caregivers are advised to reassure the PLWHA and to advise on the benefits and income support systems available.

Spiritual needs

When people are ill and activity is restricted they will often, for the first time in many busy years, have time to reflect about the meaning and purpose of their life. This may be a painful process and involve them in examining areas of guilt and conflict as well as contemplating their value and belief systems. Many will need help and support from their caregivers during this time. Given a safe, secure, loving environment free from pressure, ridicule and judgmental attitudes, people will feel more able to explore and express their spiritual needs, conflicts and problems. Caregivers need to respect people's religious beliefs, or the fact that they have no religious belief. Therefore, caregivers need to recognize that PLWHA need to have the freedom to worship according to their faith and this should be facilitated whenever possible.

According to South Coast Hospice CHBC Programme a multi-professional team needs to respond to the needs of PLWHA as outlined above (UNAIDS: 2000). Ideally, the core of the team should include nurses, a doctor, therapists, a dietician, social workers, counselors, psychologists, voluntary CHBC caregivers, and ministers of religion, either to give regular in-put or to be available when needed or wanted. Sims & Moss (1991: 19) cautions that to achieve a coordinated approach it is

important that the team as a whole agree on the overall aims of care. The aims should include the following:

- To provide for the needs of the whole person, that is, holistic care
- To treat each person as an individual, with respect and acceptance, acknowledging each person's right to privacy and confidentiality
- To give control back to the PLWHA as far as is possible
- To enhance the quality of life by good care, including aids for daily living, appropriate housing and effective symptom control, enabling the PLWHA to live life as fully as possible until death
- To facilitate a comfortable and dignified death
- To provide support and bereavement follow up to families, partners and friends, recognizing all who are of importance to the PLWHA

A need for situated learning

The Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (2003) recognizes the crucial role played by home-based care volunteers, particularly in assessing and supporting patient adherence to ART and other therapies, including locating and reaching out to patients who miss scheduled appointments, promoting continuity of care and adherence with ART regimens. The plan (2003) further argues that palliative care services can also be provided through home-based programmes working to train and support the patient's families and friends to ensure the highest achievable quality of life. This is the current situation because the public health care system is unable to absorb all terminally ill patients into their care due to the challenges of overcrowding and overloaded health care workers in public hospitals. However, the government plan is silent on the support and care that needs to be provided to those who care for others in the field of CHBC.

In this context, Boud (2001) would argue for a need for educational programmes to consider a great range of differences existing in the context of the learners. He maintains that individual learners bring into the learning situation their different aspirations, cultures and levels of knowledge. For this reason, he argues that educational programmes need to be flexible, not only in terms of situatedness and

difference, but also because work is ever changing and learners change along with it. Boud's analysis is reflected in the field of home-based care, which has undergone a significant shift since the ARV rollout programme as a component of a comprehensive plan. The Operational Plan for Management, Care and Treatment of HIV and AIDS (2003) shows clearly that the needs of both communities and caregivers have changed since the ARV rollout programme has been introduced into the system. It is therefore crucial to analyse the context that informs CHBC curricula.

In the training of CHBC learners, it is crucial to consider the context within which the voluntary caregivers operate as Boud (2001) & Boud, Cohen & Walker (1993) acknowledge that learners bring prior knowledge and experience with them to the learning situation, and attempt to situate this knowledge within an understanding of the social context. In the area of CHBC, educators might need to consider the context of care, which Foster (1996 cited in Gow & Desmond, 2002) identifies as three phases in the cycle of illness and death - that is, the illness, the death, and the long-term aftermath. The negative impact of HIV and AIDS can be felt in each phase, and that has a number of serious economic, psychological and social effects on members within a household. This is evident within households whereby young girls have often been forced into roles of care giving and at the same time have to find ways for the family to survive financially.

The context of care also suggests that the extended family should take the responsibility of care, thereby making children who are minors stay with members of the extended family after the death of parents. However, Barnett & Whiteside (2002) argue that an entity called 'the extended family' which will absorb the orphans and destitute created through AIDS-related mortality is in many circumstances non-existent. There are currently a lot of debates around this issue, particularly around the traditional role of the extended family, that include whether or not the traditional extended family system is still appropriate and if care of orphans is their responsibility. This was shown in a study conducted in 1992 in South Africa (Steinberg et al, 2000), which clearly indicated that 62% of Sowetans felt that orphans should be the responsibility of the State.

Many studies have shown that communities are incapable of providing quality care due to poverty, unemployment and the effects of AIDS. A Ugandan study conducted by Kikule (2003)²⁶ based in Kampala with 173 patients with HIV and AIDS, shows that a number of people living with HIV and AIDS would prefer to die at home, but these studies have also demonstrated that the reasons were due to the discrimination that PLWHA experienced in public hospitals. The author further reports that few participants used government health services in Uganda as they were generally poorly equipped and health staff gave priority to patients with curable conditions and did not have time for terminally ill patients. In another study, Berer (1993) reports that health professionals treat pregnant women who are subsequently found to be HIV positive differently from other pregnant women. These findings are invaluable for our understanding of community perspectives on the shift to community care. In this case, for instance, patients do not really choose to die at home, as studies reveal that they choose community care because of the ill-treatment in public hospitals, poor service delivery, and a high level of stigma in the community.

Van Dyk (2001) & Uys (2003), on the other hand, point to one of the benefits of home-based care as providing an opportunity for people to face ill health and death in familiar surroundings rather than in a hospital ward. According to Fox and Raphael (1997 cited in Nkwe-Mabua, 2000) the underlying factor in CHBC is that a patient is cared for at home where he/she is in control of his/her surroundings and enjoys the primacy and privacy of decision making. However, as it will be shown later in chapter 5, this does not imply that the caregivers, both primary and voluntary, are always ready and equipped with skills that enable them to provide such care at home. This brings into perspective the issue of their training for the caring role.

In the next section, I will provide different models of care and the aim is to demonstrate the extent of care and the responses that have been established to counteract the impact of HIV and AIDS. Akintola (2004), Uys (2003) outlines the different types of CHBC models of care that have emerged as a response to HIV and AIDS. These include the following: integrated community home-based care, single

²⁶ Report available from the Health Systems Trust website at: <http://www.hst.org.za>

service home-based care, informal home-based care, and community health workers home visits.

The different CHBC models of care

Integrated community home-based care

The Hospice Association of South Africa mainly implements this model of care. It strives to link “all the service providers with patients and their families in a continuum of care” (Uys, 2003: 5). The distinguishing feature of this model is the provision of a comprehensive health care service as it aims to ensure a “continuum of care”²⁷, that is, a swift transition from a positive test result to treatment and care. However, even though the South African community has come to recognize the crucial need to integrate prevention, care and treatment services to create a single continuum of services, shortages in health infrastructure and inadequate training facilities for health care workers remain a challenge. Besides this, there is also a shortage of health staff, overcrowding in hospitals, and lack of infrastructure to ensure effective and efficient service delivery. The Joint Civil Society Monitoring Forum (JCSMF, 2005) has observed that people who test HIV positive in public hospitals wait as long as six months for a CD4 count which could, according to the national HIV and AIDS policy, determine their readiness to initiate an ART programme. By the time people receive their CD4 count results, many of them are too weak to commence treatment.

Part of the integrated CHBC model is support for the caregivers, UNAIDS (2000) notes that a few hospices in South Africa have taken a proactive approach by providing various ongoing psychological support for caregivers. These include stress management classes, mandatory leave, and consultations with a psychologist. This demonstrates a shift of focus from the sick person to the caregivers. For example, the Centre for AIDS Development Research and Evaluation (CADRE, 2002) demonstrates the model used at South Coast Hospice in Port Shepstone, which is considered a good example of an integrated model. The project provides a comprehensive package in that it also caters for the needs of caregivers who are given

²⁷ Components of this continuum of care include prevention-related interventions; voluntary counseling and testing (VCT); medical care and treatment by a dedicated, trained medical team; psychological support; nutritional assistance; social supports; community-based services and home-based care as needed (Operational Plan, 2003)

leave at least twice a year for two weeks at a time. They also meet with an outside psychologist once a month to help them deal with stress. In addition, every Tuesday the caregivers are given time to talk about AIDS patients who have died, sharing their experiences with the psychologist, and addressing the positive and negative aspects of their care. However, I will later show in chapter 4 how different is the kind of support that is provided to CHBC voluntary caregivers working in the area of Mpophomeni.

Single service home-based care

This is the most common model of care in South Africa. In describing this model, Akintola (2004: 3) refers to it as a “community home-visiting care programme”, while Uys (2003: 7) uses the concept of “single service home-based”. Caregivers recruited into such programmes are usually targeted by non-profit making organizations such as local churches, CBOs, and NGOs. They are recruited to provide voluntary basic nursing services to PLWHAs and their families. According to Akintola (2004), the services provided also include emotional, spiritual, and physical support. The CHBC training of caregivers in such instances is organized and arranged by the organizations themselves according to their training needs. This study focuses on this model of care, using voluntary caregivers working in the field of CHBC in the area of Mpophomeni.

Informal home-based care

This model of care takes place within the home whereby family members care for their own family member. Uys (2003) notes that external support is not always available from social networks, and members function in this environment without any formal training since members do not belong to any organization. As much as the ideal integrated model is the most desirable, it is not usually available. Uys (2003: 7) concludes that this model of care “is very taxing, since the caregiver may lack the necessary skill, knowledge, and emotional support”.

Community health workers (CHW) home visits

The National Department of Social Development is responsible for the recruitment and deployment of community health workers. While the focus of their work is not

on providing the common duties of CHBC such as washing and feeding patients, they also visit patients at home. In the Department of Social Development's website (2004), CHW's role is acknowledged as that of providing the following community services with regard to health:

- Mobilise community members
- Act as advocates to improve health
- Coordinate the access of other health workers
- Provide specified primary health care services to community members
- Provide basic counseling service
- Disseminate health information
- Carry out health promotion activities
- Transfer wellness skills to community members

It needs to be noted that CHW work is fixed with regular hours as opposed to caregivers in the single-service home-based care and informal home-based care. According to the National Department of Social Development (2004), CHW's also receive a minimum stipend of R1000, and the maximum of R2000 is often negotiated on the basis of additional competencies, number of beneficiaries and area of work.

Even though the length and format of training of CHW's could not be accessed, the little that is known about the training is that it should conform to national standards registered on the National Qualifications Framework (NQF). The training providers also need to be accredited by the Health and Welfare SETA to be able to offer programmes of learning for CHW. The Education and Training SETA and the Health and Welfare SETA are required to accredit a competent provider for the training of trainers of CHW's (Department of Social Development, 2005)

Having outlined the needs of PLWHAs and their families, and also the models of care that have been established, the next section looks at the needs of caregivers.

The needs of caregivers

In a hierarchy of needs, studies have shown that caregivers also have basic needs almost similar to those of beneficiaries of care (PLWHA and their families), that is, emotional, social, and financial needs. Blinkhoff et al (1999 cited in Miller 2000)

illustrates some of the needs of caregivers in a study conducted with caregivers in Zambia. Having outlined all the major successes within the programme, one volunteer was quoted saying:

...sometimes I do think about giving up, like during the rainy season when my roof is leaking. And sometimes the work is very unpleasant. Once I went into the house of my patient, and as I opened the door there was an overpowering smell like a decaying corpse. There on a mat in front of me was this poor bundle of humanity, like a lamb waiting to be slaughtered. I opened the window and saw that the man's body was covered in sores and maggots. And the pain in his eyes... There I was, alone with this burden. I thought 'Doctor, where are you? Sister, where are you? This is unbearable. O God, how can I go on? Isn't there someone out there who cares about me, a volunteer with limited knowledge left to do this work?' Sometimes I wish there was some kind of reward for what we do. But I can't stop now. I'm too deeply involved. My finger is woven into the basket.

The study outlined above demonstrates a need for emotional support and a need for financial reward in volunteers.

In another study conducted with Australian volunteers, Guinan et al (1991 cited in Miller 2000) identify levels of stress in voluntary caregivers. Using factor analysis, they found that the four primary stress factors included emotional overload, patient's problems for which they felt inadequately prepared, lack of support, and lack of quality training. Similarly, in an analysis of data on religious volunteers in the United States, Bennett, Ross & Sunderland (1996) found that burnout in volunteers was associated with a felt lack of adequate training, and an absence of personal effectiveness. Both studies clearly demonstrate the presence of stress in the absence of adequate training to help volunteers fulfil their role effectively, and this demonstrates a need for proper training in preparing the caregivers for their task.

The literature review shows that not much emphasis has been placed on the needs of caregivers. This is supported in Miller (2000) who observes that there is a lack of documentation about the efforts of voluntary caregivers given their importance, and

certainly about their personal experiences of the burdens of HIV and AIDS care. Miller's analysis is illustrated in a case study conducted by the UNAIDS (2000) which focused on six HIV/AIDS-focused organizations in Uganda and seven providers in South Africa. The report demonstrates that the focus for many major organizations in the field of CHBC is to train and supervise volunteers (UNAIDS, 2000), i.e. the emphasis is on the practical aspect of care. For example, one CHBC organization used as a case study illustrates their understanding of "caring for carers" as fulfilling the following functions:

- To send their nurses with specialist skills in palliative care into the field with the volunteers. However, the emphasis is made that when they are in the field with the volunteers they are not allowed to give hands-on care themselves – their job is to supervise the volunteer.
- To introduce volunteers to staff at the local clinic and to encourage a good working relationship.
- To build their confidence so that they function effectively and efficiently in their roles as carers.
- To provide a two-day training for volunteers who are literate on record keeping (UNAIDS: 2000: 49).

Reflecting on the challenges in CHBC and the needs of caregivers as outlined above, it goes without saying that any training curriculum should consider the context in which caregivers operate. As I will show later in chapter 4, my study shows similar findings.

2.7 CONCLUSION

This chapter presented the literature review, which provides a detailed analysis of the current literature available in the field of CHBC. Inspired by the feminists' and the Freirean approaches, the study presented a critical analysis of excessive reliance on poor communities, utilizing poor women in particular as a source of care initiatives in CHBC. The chapter further examined not only the benefits of CHBC to PLWHAs but also the needs of caregivers, which need to be addressed so that they could provide quality care over a sustained period, calling for a need for situated learning. The different models of care were also outlined.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter outlines the research methods used in the study, it highlights key differences between qualitative and quantitative studies, and justifies the chosen research design. The study employs different tools of data collection, including observation, semi-structured interviews, and documents review. Therefore, a brief outline is provided to explain the reasons for using each one of them. As the main objective of this study was to explore whether the training given to community home-based caregivers prepares them to assist people living with HIV and AIDS, I, therefore, selected a qualitative design as best suited the objective of the study.

3.2 RESEARCH DESIGN

According to Merriam & Simpson (1995: 2), research is “a systematic process of data collection and analysis aimed at discovering something that we did not know before engaging in the process”. Hence, an important aspect of research is discovery. A research design as defined by Mouton (2001: 55) is “a plan or blueprint of how one intends conducting research”. A plan should specify how the research is going to be executed in such a manner that it answers the research question (Terre Blanche & Durrheim, 1999), meaning that the nature of the research dictates the research design.

In planning a research project, Terre Blanche & Durrheim (1999: 43) point out that a researcher must make decisions regarding all three ways in which types of research are distinguished: 1) exploratory, descriptive and explanatory; 2) applied and basic, and 3) quantitative and qualitative. Terre Blanche & Durrheim (1999) suggest that qualitative research is more commonly used to inductively explore phenomena, and provide thick (i.e. detailed) descriptions of phenomena. The next section will help to clarify the differences between quantitative and qualitative study, and the discussion will also highlight the reasons behind my choice of design.

3.3 QUANTITATIVE VERSUS QUALITATIVE RESEARCH

There are inherent differences found between the two methods of research. According to Mouton & Marais (1994) quantitative approach may be described in general terms as that approach to research in the social sciences that is more highly formalized as well as more explicitly controlled, with a range that is more exactly defined, and which, in terms of the methods used, is relatively close to the physical sciences. On the other hand, qualitative approaches are those approaches in which the procedures are not as strictly formalized, while the scope is more likely to be undefined, and a more philosophical mode of operation is adopted.

Terre Blanche & Durrheim (1999) observe that quantitative researchers collect data in the form of numbers and use statistical types of data analysis. They employ methods that begin with a series of predetermined categories, usually embodied in standardized quantitative measures, and use this data to make broad and generalizable comparisons. In contrast, qualitative researchers collect data in the form of written or spoken language, or in the form of observations that are recorded in language, and analyse the data by identifying and categorizing themes (Terre Blanche & Durrheim 1999). As a result, qualitative methods allow the researcher to study selected issues in depth, openness and detail as they identify and attempt to understand the categories of information that emerge from the data. In consequence, according to Mouton & Marais (1994), the qualitative researcher tends to become more involved with the phenomenon, while the quantitative researcher adopts a more distanced position. It is against this background that Maykut & Morehouse (1994) point out that research studies that are qualitative are designed to discover what can be learned about some phenomena of interest, particularly social phenomena where people are the participants. Interestingly, the outcome of any of these studies is not the generalization of results, but rather, a deeper understanding of experience from the perspectives of the participants selected for study.

I have intentionally chosen a qualitative design as it best addresses the purpose of this study, particularly because of its open, fluid and changeable features as noted in Terre Blanche & Durrheim (1999). Lincoln and Guba 1985 & Stake 1975 (cited in Maykut & Morehouse, 1994) point out that due to this emergent nature of qualitative research,

a qualitative researcher can discover features which were not originally planned for in research design. Important leads are identified in the early phases of data analysis and pursued by asking new questions, observing new situations or previous situations with a slightly different lens, or examining previously unimportant documents. These characteristics are very crucial and much needed for this particular study where I hoped to learn from the experiences of voluntary caregivers and their CHBC trainers.

3.4 SAMPLING

Terre Blanche & Durrheim (1999: 44) assert that sampling involves decisions about which “people, settings, events, behaviours and/or social processes to observe”. They further recognize that the main concern in sampling is representation, that is, the aim is to select a sample that will embody the population from which the researcher aims to draw conclusions. In qualitative research, participants are carefully selected for inclusion, based on the possibility that each participant (or setting) will expand the variability of the sample (Maykut & Morehouse, 1994). According to Merriam & Simpson (1995: 100) this is known as “a purposeful (non-random) sample, one from which a researcher can learn the most”.

As for the unit of analysis in this particular study, the sample consisted of 10 community caregivers who have been trained in CHBC, 4 CHBC trainers, and a counseling trainer. While it is prudent to have a large sample size, it needs to be acknowledged that this is a mini-dissertation, therefore this small sample size is determined in part by practical constraints. The chosen selection is partially supported by Terre Blanche & Durrheim (1999) in saying that the types of research that are less concerned with statistical accuracy than they are with detailed and in-depth analysis do not draw large or random samples, hence qualitative research which is interpretive in nature. Instead, various types of purposeful (i.e. non-random) sampling may be used. Therefore, Terre Blanche & Durrheim (1999: 41) recognize that qualitative research aims only to generalize the findings of a study to the specific context under scrutiny in order to assist decision-making in drawing conclusions about the particular problems with which they are dealing: “rather than insisting that samples should be representative, qualitative researchers ensure that their findings are transferable, that is, they help other contexts or groups similar to those studied.”

The women involved in the study were recruited through the AIDS organization in the study. This organization collaborates with various CBOs in the community for the purpose of sharing and also building capacity. The community caregivers come from 3 different CBOs that operate in the area of CHBC. The women involved in CHBC from these 3 organizations make a total number of 16 individuals. The process that was being followed began with a briefing with a staff member of the AIDS organization under study, who coordinates the CHBC project, at a meeting held on 28 July 2003. This provided an opportunity to outline the goals and objectives of the study, and also for me to begin exploring the service provider's own understanding regarding the key aspects of care in the CHBC context.

On 29 July 2003, I, together with the CHBC Coordinator met with the group of women who provide CHBC services within Mpophomeni Township. The Centre is used by the CHBC Coordinator to run meetings and provide resources including pre- and post-test counseling to needy members of the community. The main purpose of meeting the entire group of women was to explain the nature and purpose of the research, and it was also stressed that participation needed to be voluntary. The response was quite positive as many women mentioned the need and importance of being provided with an opportunity to talk about their own needs. The next step was to set dates for interviews with the 10 women from among those present who volunteered to be interviewed.

3.5 METHODS OF DATA COLLECTION

Data is the basic material with which researchers work. As noted in the previous section, interpretive researchers maintain that the meaning of a phenomenon varies across contexts, and they adopt a more inductive approach to data collection, investigating how categories of observation emerge in context.

Terre Blanche & Durrheim (1999) and Merriam & Simpson (1995) outline data collection mostly favoured by qualitative researchers, which were also employed in this study, that is, observations, interviews, and analyses of written documents. Merriam & Simpson (1995: 100) argue that these methods:

Permit rich and detailed observations of a few cases, and allow the researcher to build up an understanding of phenomena through observing particular instances of the phenomena as they emerge in specific contexts.

The three commonly used methods in data collection are briefly discussed below.

Observation

Participant observation, according to Terre Blanche & Durrheim (1999), affords the researcher an opportunity to participate in the setting being studied. Consequently, it takes place while things are actually happening, and thus gets the researcher even closer to the action. In so doing, participant observation helps the researcher to understand the group being studied from the inside out.

This method of data collection was effectively adopted in the CHBC training whereby I participated in a one-week home based care training conducted by the CHBC organization under investigation. The specified training provider was chosen because I had earlier discovered that the organization provides CHBC training for voluntary caregivers to networking partners. The purpose of observation was threefold, viz:

- To find out what the CHBC training entails, by exploring the content of the curriculum;
- To establish how the training encourages caregivers to reflect on their own experiences and expectations;
- To determine how the training builds on caregivers' prior experience while challenging unhelpful personal issues and behaviours learnt previously.

As highlighted in Bless & Higson-Smith (2000) & Terre Blanche & Durrheim (1999) a major weakness in participant observation is that it can be a particularly time-consuming and demanding way of collecting data. Using this method of data collection provided me an opportunity to take field notes during training sessions, describing in detail what participants did and said.

First, I had approached the Senior Training Officer of the CHBC training organization to obtain permission to observe the training. It was difficult for the organization to

grant me access to observe their training sessions, but in terms of ethical considerations I had to negotiate access. If that was not the case, I could have just silently sneaked into the training course for fear of being denied access, particularly because I had already experienced it in other organizations approached earlier.

Observations during the course of the study also incorporated visits to two different homes of PLWHA in the local community, in the company of voluntary caregivers already working in the field of CHBC. The aim was to ascertain how voluntary caregivers carry out their daily tasks and also observe the kind of information they provide to PLWHA and their families. As stated earlier, a total number of 10 community caregivers were recruited through the AIDS organization under study. Six women from the sample preferred that the interview would take place in their organization, while the other four women requested that I conducted their interviews at their homes, as they felt that there would be minimal interruptions in that setting since children are at school during the day. This provided a unique opportunity to observe dynamics within the homes of caregivers, including the kind of environment and conditions they live under. During observations, I kept thinking about the research process and the kind of questions that need to be answered as suggested in Terre Blanche & Durrheim (1999). Each day, two interviews were conducted, which lasted for about 30 to 45 minutes.

It needs to be noted that throughout the process of observation, I also made good use of key informants. Terre Blanche & Durrheim (1999: 138) define a key informant as somebody “the researcher gets on with and who is part of and knows the culture being studied”. This is someone who also likes talking and sharing his/her perspectives. Such individuals were very resourceful during the CHBC training. These informal conversations took place over tea or lunch, thus opening possibilities to other unexplored phenomena.

Interviews

In their analysis, Terre Blanche & Durrheim (1999) maintain that conducting an interview is a more natural form of interacting with people as researchers get an opportunity to know people quite intimately, so as to really understand how they think and feel. Accordingly, Dexter (1970: 136 cited in Merriam & Simpson, 1995: 106) defines an interview as a “conversation with a purpose”.

Merriam (1988 cited in Merriam & Simpson, 1995) describes a semi-structured interview as probably the most used method of data collection in qualitative studies in adult education and training. According to Merriam & Simpson (1995) by using an open-ended format, investigators hope to avoid predetermining the subjects' responses, and hence, their views of reality. It is against this background that the semi-structured interview was found to be best suited in this particular study since one of the major aims of the study was to hear about the experiences and feelings of women voluntary caregivers involved in CHBC. I conducted semi-structured interviews in order to provide interviewees an opportunity to talk in some depth about their feelings and experiences. This technique allowed the freedom to expand on the topic as they saw fit.

As suggested in Seale (1998 cited in Merriam & Simpson, 1995), I prepared an interview-guide beforehand so as to have a sense of the kinds of feelings and experiences I would want to explore. When conducting such interviews, a checklist acted as an aid, helping me to decide what to turn to next as the interview proceeded (see Appendix 3 – interview guide).

The interviews conducted during the period of the study consisted of the following individuals:

- 10 voluntary caregivers, and their CHBC Coordinator from the AIDS organization under study.
- 4 CHBC trainers, i.e. three women and one male from the CHBC training organization.
- The Head of the Training Division from St. John's Ambulance in Durban.
- A counseling trainer from McCord's Hospital in Durban

- A CHBC Coordinator from the AIDS organization under study.

In conducting the actual interviews, I followed the guidelines provided by Terre Blanche & Durrheim (1999) therefore, the interviews began with a summary of what the research is about. Thereafter, a short relaxed conversation would follow, which kept both the respondents and I talking and this helped to build trust. During the interview itself, I tried my best to keep the respondents interested in the conversation, while noting both verbal and non-verbal communication during the conversation. The interview questions entailed information on age, marital status, household income, employment history, training methodology, content, etc. As the question of age is a sensitive one, interviewees were asked to approximate their age in a series of age bands (for example, 14 – 19, 20 – 25, 26 - 34). However, all the respondents were decidedly forthcoming in providing their accurate ages – something which was helpful in obtaining accurate information.

I soon realized that some interviewees were easier to talk to than others, but on average almost all of them made an attempt to talk in some depth about their feelings and experiences with the help of my incisive questions. I ensured that each respondent was comfortable with their responses being taken down on paper, therefore their consent needed to be solicited before beginning the interview. Some stressed the importance of protecting their identities by not mentioning their names in the final document. In addressing this need, I also took a conscious decision not to disclose the name of the organization where the study was undertaken. As it will be observed in the next chapter, some of the information shared by community caregivers about themselves is private and confidential. In order to protect them from stigma surrounding HIV and AIDS, I deemed it necessary not to mention the individual organizations under investigation.

Documentary review

Documents are a natural source of information and usually already exist within the context of the study. Guba & Lincoln (1981 cited in Merriam & Simpson, 1995: 106) point out that as a resource, documents and records have the following characteristics:

- Easily accessible, low-cost, or free

- Constitute a legally unquestionable base from which to defend oneself against allegations
- Represent the context of the research problem
- May be more objective sources of information than an interview
- Provide a base for further inquiry

Therefore, four training manuals from major organizations²⁸ in the field of CHBC were reviewed and analysed. The ultimate aim was to gain insight on what is offered in such trainings by taking a closer look at the content of each training, the length of training, etc, and find out if there are any differences.

Additional documents from the field of HIV and AIDS counseling²⁹ were also reviewed, and that included training manuals from four different organizations. Other additional resources were the annual reports, previous minutes of meetings and other relevant documents from the AIDS organization under investigation.

As suggested in Merriam & Simpson (1995), I also kept a diary each day while conducting fieldwork in order to record personal feelings, ideas, impressions, or insights as events unfolded in their various settings. Merriam & Simpson (1995) further state that the diary becomes a source of data and allows researchers to trace their own development and biases throughout the course of the investigation.

3.6 FINDINGS AND DATA ANALYSIS

According to Merriam & Simpson (1995) it is possible to integrate the findings with the discussion; in that way, the interpretation of data is interwoven with the actual findings. However, this view is contestable, as other authors would argue that by separating the findings from the analysis, a researcher lets the data speak for itself before interpreting it. Mouton (2001: 124), for example, maintains that:

The results from the fieldwork may be organized in one or more chapters, depending on the nature of the study, the research objectives,

²⁸ The names of the organizations are withheld to ensure anonymity

²⁹ The names of the organizations are not included to ensure anonymity

the complexity of the research design, and the amount of data collected.

Reflecting on the research design chosen for this particular study, it became apparent that if the findings were to be integrated with the analysis, the voices of the research participants might get lost in the process. Writing the findings in a separate chapter, afforded me the opportunity for using quotations, which tend to bring qualitative reports to life and present the reality of events. As stated earlier, qualitative studies are most effectively presented within a rich narrative. In so doing, a qualitative research report characterized by rich description hopes to provide the reader with enough information to determine whether the findings of the study possibly apply to other people or settings.

Chapter 4 will therefore outline the findings, this is followed by chapter 5, which covers the analysis of the findings. Terre Blanche & Durrheim (1999: 47) perceive the aim of data analysis as “to transform information (data) into an answer to the original research question”. Simply stated, this section aims to describe what I have discovered as a result of the investigation.

Given the nature of the research design, data analysis began by identifying themes and relationships. According to Terre Blanche & Durrheim (1999), themes should ideally arise naturally from the data, but at the same time they should also have a bearing on the research question. Therefore in chapter 5, I used my field notes and interview transcripts to analyse data. Data analysis consisted of constantly looking for similarities and differences, for groupings, patterns and items of particular significance as suggested in Bell (1993) and also in Terre Blanche & Durrheim (1999).

3.7 ETHICAL CONSIDERATIONS

Informed consent

To arrange interviews with the community caregivers, the starting point was to solicit permission from the Management of the CHBC training organization. Even after they had granted permission, it was still deemed necessary to gain informed consent from

the research participants themselves. Thereafter, I spent quality time with the respondents as a group to highlight the purpose and objectives of the study. Again, the participants in the study were informed of all aspects of the research, which might reasonably be expected to influence their willingness to participate in the study. The main aim for doing this was to ensure that there were no unfulfilled expectations. Consequently, when women in the study eventually agreed to participate, their decision was informed by knowledge about the research. It was also made clear from the outset that the respondents were at liberty to withdraw from the study at any time.

Confidentiality and anonymity

Respondents were assured that all information obtained during the research study will be kept confidential, however, they were informed about the importance of disseminating the research findings to inform the practice of CHBC. To protect their identities, the names of the CHBC training organization and AIDS organization in which the voluntary caregivers were recruited, including the names of all women respondents in the study were given pseudonyms.

Dealing with my own bias

In approaching this study, I was acutely aware of the extent to which I was affected by HIV and AIDS, having lost two of my sisters to the pandemic. The experience of undertaking this research helped me on two levels: Firstly, it empowered me to own my sense of loss as I felt I was contributing something towards the challenges posed by HIV and AIDS. Secondly, I was prompted to delve deeper into issues of care, having witnessed the difficulties confronting carers and the unavailability of care when it is most needed in a family with a patient. Therefore, I acknowledge my own bias and rationale for undertaking this study, however the questionnaire that I developed for the purpose of this study helped me to focus on the objectives of the study. Throughout the process of writing this report, therefore, I strove to record experiences from the perspective of the individual participants, bracketing my own taken-for-granted assumptions and perceptions.

3.8 LIMITATIONS OF THE STUDY

Lack of access to beneficiaries of CHBC in the home

It was also the interest of this study to interview beneficiaries of the services provided by voluntary caregivers, that is, conducting interviews with PLWHA and their families. However due to the nature of the disease and the issues associated with HIV AND AIDS stigma, it became difficult to fulfill this objective. I chose to be sensitive to the issues and not conduct interviews in individual homes. However, an opportunity to observe in two homes while in the company of community caregivers provided key insights to the challenges and opportunities presented to women volunteers.

Distance and accessibility

Time constraints were an obvious obstacle for conducting a study of this nature. Having being based in Durban, while the fieldwork was done in Mpophomeni, I had to travel long distances to conduct the interviews. This had cost implications. The problem was exacerbated by the fact that there was no specific funding available to cover costs for the actual responsibilities related to fieldwork, so the costs were borne by me. Again, I had to do a lot of traveling within Mpophomeni Township, as some volunteers were only available in their own homes, which were long distances apart.

Lack of access to major CHBC organizations

It is worth mentioning that a few organizations, which were initially approached, were reluctant to participate in this study. This could suggest unfounded fear on their part that the research might elicit feelings or behaviour that the organizers might fail to deal with.

Inability to complete the study within the given timeframe

The study was conducted in 2003 with the intention of submitting the final document in February 2004. However, the study could not be completed within the allotted time due to unforeseen circumstances. I sought to update the information by re-conducting some interviews with the research participants in mid-2005. I also updated myself on current research with regards to voluntary caregivers as evidenced in chapter 2.

3.9 CONCLUSION

The chapter presented the research methodology used in this study, and the discussion on the rationale for selecting this research paradigm was also presented. It went further to look at the strengths and weaknesses in my choice of design. By looking at the characteristics of qualitative research, it could be conclusively mentioned that the qualitative research is appropriate in addressing the research questions in this particular study, as the primary focus is on eliciting as much as I could about the work performed by voluntary caregivers in the area of community home-based care (CHBC). In doing this, I hope to use a flexible design where nothing is cast in stone, thus effectively analyzing issues from the perspectives of the participants themselves.

The next chapter explores findings of the research study.

CHAPTER 4

PRESENTATION OF FINDINGS

4.1 INTRODUCTION

This chapter presents the findings from the study. As reflected in the previous chapter, the study respondents consisted of women voluntary caregivers and their coordinator, CHBC trainers and an HIV/AIDS counseling trainer as key informants. To fulfill the main objective of qualitative research, which aims at learning from the experiences and stories of the participants, an attempt was made to separate the findings from the interpretation, so as to let the data speak for itself. The overall objective of this chapter is to paint a vivid picture of the life of a voluntary caregiver in the field of community home-based care. In support of this task, I wanted to hear their own stories, to have them talk about the challenges they experience, how this training opportunity has helped them to process and deal with those challenges, and whether, and how, it has motivated them to share the lessons learned and knowledge gained in their communities in general.

To illustrate the psycho-socio, economic, and cultural environment in which caregivers operate, the subsequent discussion will begin by outlining the profiles of women interviewed. This will entail personal details, level of education, employment history, HIV status, economic status and the reasons why they became volunteers. This is followed by a description of the daily life of a caregiver: their daily tasks, roles and responsibilities, challenges and success stories in their field of work. I will further explore the kind of preparation given to the caregiver, by outlining their training programme.

4.2 PROFILES OF WOMEN VOLUNTEERS INTERVIEWED³⁰

The fieldwork for this study was initially undertaken in July 2003. Soon after the introduction of ARVs and other developments in the HIV and AIDS field, voluntary caregivers were visited again in July 2005 to allow me a view of changes and developments in the system over the previous two years.

³⁰ All respondents have been assigned pseudonyms to ensure confidentiality and anonymity.

It needs to be mentioned that during the initial interviews in 2003, voluntary caregivers worked without any incentives. However, during my field visit in July 2005 they reported that they were provided with a monthly allowance of R100 for a short period of time. A generous donor, who decided at a later stage to review this approach to community work, had made this grant possible. Although this was a nominal amount, its subsequent withdrawal led to a decrease in volunteers' activities. However, I managed to interview all the women who participated in the initial phase of the study during my second visit in July 2005, even though some were no longer as enthusiastic and passionate about voluntary care as they were when I first met them.

During the final visit in July 2005, I also discovered that the socio-economic conditions of the four voluntary caregivers who now have part-time employment have changed for the better. The four women are currently employed by the local clinic to conduct home visits in order to check on people who are about to commence an ARV treatment programme. Three of the other women still spend time on voluntary CHBC work.

Lungi

Lungi is 44 and has experience of many years of employment as a domestic worker.

Lungi had two distant relatives who died of AIDS. Since childhood, she has been helping the sick and the dying and that is why she felt an attraction to get involved in this type of work. She is married with 3 children and her husband, who is employed, provides for the family. In terms of HIV and AIDS training, Lungi has been trained in both community home-based care and counseling skills. She is one of the women who are now in employment at the clinic, providing assistance in the ARV rollout programme. She visits AIDS patients who are about to embark on the ARV treatment programme to check their readiness using the criteria described above.

When asked about the reasons for getting involved in care for the sick, Lungi responded that she gets her motivation from her Christian faith, "*our christian faith tells us that faith without good deeds is dead.*" She further explained that the support she gets from her husband is vital:

I am very lucky that my husband is in full-time employment, because he is able to provide for the entire family. The monthly salary of R600 from the Communicable Diseases Clinic (CDC) only takes care of my cosmetics and covers travel costs of children to school.

Sibongile

Sibongile is 33 years old and had never been in formal employment. She was the primary caregiver to her uncle who died of AIDS in 1995. Sibongile only completed Standard 7 (Grade 9) in 1986 and reasons for not studying further were not given. She comes from a family of nine children, four of whom have moved out of the house. In 2005, she reported that she has been involved in voluntary work for five years. She saw a great need to care for the sick since she witnessed many people who died with no one to care for them. In terms of HIV and AIDS training, Sibongile has been trained in both community home-based care and counseling skills. Sibongile is one of the four women who have been described above. She temporarily works for the local clinic on their ARV rollout programmes, while she continues to offer voluntary care in CHBC.

When asked about the source of her motivation to get involved in such work, Sibongile reported she enjoys helping other people and she could not imagine herself in any other place except in homes of those who are ill. According to her, she feels 'called' to the kind of work that she is doing:

“What would my patients be without me? I am the only person that they share their secrets, pain and joy with because their families and friends have abandoned them, and my faith keeps telling me that that is our calling as people of God.”

Sibusisiwe

A woman of 27, Sibusisiwe lives positively with HIV and had never been in formal employment. In terms of her HIV positive status, she revealed that she has neither disclosed her HIV status to the members of her family nor to other voluntary caregivers. She comes from a family of twelve children and she is the sixth child. One of her sisters died of AIDS in 2001 and her uncle died from the same disease in

2003. After her sister's death she felt motivated to get involved in AIDS work. Her father died when she was six years old and her mother who was a domestic worker, could only educate Sibusisiwe up to Standard 7 (Grade 9). At present the family depends on a foster care grant that is received in aid of her four nieces. Sibusisiwe has been previously trained in community home-based care and bereavement counseling. She is also one of the women who currently works on a temporarily basis for the local clinic in their ARV rollout programme, and she offers ongoing support to AIDS patients on CHBC programme.

When asked what motivated her to get involved in helping sick people, Sibusisiwe revealed that knowing her HIV positive status made her realize the need to help others in similar situation. Sibusisiwe's concern is that she currently lives with her boyfriend who does not want to go for HIV testing. She could be heard expressing her concern as follows:

“He is the first man I ever slept with and he is also aware of my current HIV status but he tells me that he is not prepared to use condoms. I am aware of the risks, but he feeds and clothes me and also provides for my immediate family – so, he is all that I have”.

Poverty
takes them
to take risks

Phumzile

Phumzile is a 22 year-old young woman who has never been employed. Her father has a drinking problem and fails to support the family. Her mother is also unemployed. Phumzile studied up to Standard 9 (Grade 11) and funds did not permit her to further her education. She had a sister who died of AIDS in 1996. Phumzile has been trained in both community home-based care and HIV and AIDS counseling. I learnt during the final visit in July 2005 that Phumzile has also been temporarily employed by the clinic, which offers the ARV rollout programme. Unlike the three other voluntary caregivers who decided to continue in CHBC while doing this formal employment, she chose to leave the AIDS organization where she was offering voluntary services.

When asked about the reasons for getting involved in home care, Phumzile reported that she needed to gain experience in order to get formal employment as she needs to

support her family. She also stressed the need to escape boredom and loneliness at home, as she noted:

I find it very boring to sit at home all day doing nothing. Again, your needs and interests are ignored and overlooked by those close to you, because you seem useless when you are unemployed.

Nonjabulo

Nonjabulo is a woman of 29 years, who comes from a family of eight children, three of whom are still at school-going age. After the death of her mother in 1989, the father remarried and moved out of the house to settle with his new wife. Nonjabulo has become the head of the house since she is the eldest in the family. She completed matric in 1992 but unfortunately she never had the financial means to proceed to tertiary level. Her dream was to become a teacher and, seeing that she could not fulfill her dream, she decided to become a voluntary caregiver to assist affected families. Nonjabulo had never been in formal employment and she has a sister who lives with HIV. Nonjabulo has been trained only in HIV and AIDS counseling.

Asked what motivated her to get involved in caring for sick people, she responded by saying:

Buyi “It is better than sitting at home doing nothing, what would you be doing at home all day? At least in doing home-based care, you are always in the company of others.”

Since the initial interviews in 2003, Nonjabulo has moved on to formal employment. When I visited her at her workplace during the field visits in July 2005, she told me that the possession of a drivers' license put her in an advantageous position for a job.

Buyi

Buyi is 23 years old and has never been employed. She studied up to Standard 9 (Grade 11) and had to drop out of school because of an early pregnancy. She now has two children and lives positively with HIV. Her motivation for getting involved in caring for the sick comes from knowing that one day she will also fall ill and need

someone to care for her. Both her parents are unemployed but she gets social grants³¹ for her two children, which also help to feed her entire family of seven. A child support grant is R180 per month, which gives Buyi and her family a total of R360 each month for her two children. Buyi has received training in community home-based care. However, she is still a voluntary caregiver with no income.

Smangele

Smangele is 29 years old and has never been employed. She comes from a family of five children. She is the third child. She looked after her uncle until he died of AIDS in 1997. She lives with her parents who are both unemployed. The mother receives a disability grant because of a severe form of diabetes. The father was retrenched from SARMCOL in 1984 while Smangele was doing Standard 4 (Grade 6). Therefore, after completing her matric she could not afford tertiary education. The father today manages a vegetable garden, the produce of which is sold for income to sustain the family. Smangele has received extensive training in community home-based care, HIV AND AIDS counseling, bereavement counseling, and also training on memory boxes for orphaned children³². During the final interviews with the voluntary caregivers in July 2005, Smangele informed me that she was on the waiting list of prospective community health workers³³ to be employed soon by the government. Asked how she became included on the list, she mentioned that someone from the Department of Health who knew that the programme needed new recruits approached her, together with a friend. Seeing that they had experience in community work, she was targeted as a potential candidate.

³¹ This chapter will show later that social grants on their own cannot alleviate poverty, but only help people keep their heads above the water. The work conducted by the Black Sash (www.blacksash.org.za) has shown that the issue of access to social grants remains a challenge. Many families who are eligible to receive grants do not have the necessary documents to lodge applications for such grants. The following social assistance grants are currently available in South Africa: Care Dependency/Disability Grant (R700), Foster Care Grant (R580), Child Support Grant (R180), Social Relief of Distress Grant (food vouchers), and old age pension (R700).

³² A toolkit used to assist orphans to deal with grief and loss in their own lives. The process entails a personal journey for each child towards inner healing after the loss of loved ones. Orphans are encouraged to create a wonderful box to keep mementoes of their loved ones. It helps them remember the people they miss or an important event in their lives with the loved ones who have passed on. They decorate these boxes and fill them with items that remind them of special times, events, or people they miss.

³³ The role of a community health worker is explained in Chapter 2.

Nokuthula

Nokuthula is a 31 year-old woman who comes from a family of five children and she is the second child. The father died in 1988 and the mother works two days a week as a domestic worker. The family's other source of income is the grandmother's pension. She dropped out of school in Standard 9 (Grade 11) in 1990 due to financial constraints. One of her brothers also dropped out of school in Standard 7 (Grade 9) for the same reasons. Her cousin died of AIDS in 1999, so Nokuthula was motivated to get involved in voluntary work. She has never been in formal employment. She has only been trained in community home-based care and she is on the same list for a potential job in community health work, as Smangele.

Dudu

Dudu is 31 years old, married with four children and has once worked as a domestic worker, looking after an elderly person until he passed away. Her motivation for getting involved in voluntary work comes from her long-cherished desire to become a nurse. Her husband is employed as a veterinary assistant and earns R1 800 a month, which helps to support the family. Dudu failed matric and never wrote any supplementary exams as she was preparing to get married. She is living positively with HIV. Both her parents are unemployed and live in an informal settlement in Howick. Dudu reported that she has been well trained in community home-based care, counseling, and bereavement counseling. Regarding her training in CHBC, she disclosed how she was once overwhelmed by the fear of an HIV test, and it was only after her HIV and AIDS counseling training three years later that she decided to go for voluntary counseling and testing (VCT). She later remarked how fortunate she was to know her status because she can take care of herself,

“...unlike my peers whom I work with in the CHBC programme who are overwhelmed by fear of HIV testing”.

Zandile

Zandile is 30 years of age and has never been employed. She is living positively with HIV. She discovered her HIV status by getting tested after losing a brother to AIDS in 2000. The loss of her brother motivated her to go for a VCT, and later became involved in voluntary care after having learnt about her HIV positive status. Both her

parents are pensioners. Zandile has two children who currently receive social grants. She has only been trained in HIV AND AIDS counseling, but she effectively provides community home-based care services in the area of Mpophomeni.

Table 2: Summary of the socio-economic status, and previous training of CHBC voluntary caregivers

NAME	AGE	MARITAL STATUS (M/S) ³⁴	HIV STATUS (+/-)	EMPLOYMENT HISTORY (Y/N) ³⁵	CHBC TRAINING (Y/N)	HIV/AIDS COUNSELING (Y/N)	OTHER TRAININ (Y/N)
LUNGI	44	M	-	Y	Y	Y	N
SIBONGILE	33	S	-	Y	Y	Y	N
SIBUSISIWE	27	S	HIV+ ³⁶	Y	Y	N	Y
PHUMZILE	22	S	-	Y	Y	Y	N
NONJABULO	29	S	- ³⁷	N	N	Y	N
BUYI	23	S	-	N	Y	N	N
SMANGELE	29	S	-	N	Y	Y	Y
NOKUTHULA	31	S	-	N	Y	N	N
DUDU	31	M	HIV+	Y	Y	Y	Y
ZANDILE	30	S	HIV+	N	N	Y	N

Overall, 7 out of the 10 voluntary caregivers admitted that they are doing the work because it is better than sitting at home doing nothing. They maintained that if they were to find formal employment they would leave CHBC, while the other three voluntary caregivers continuously reported that it was difficult to turn their backs on their patients because they would feel neglected and betrayed.

4.3 THE CONTEXT IN WHICH CAREGIVERS OPERATE

A typical day in the life of a voluntary caregiver

After getting a general sense of who the voluntary caregivers were and where they come from, I began asking about the specific duties that they need to fulfill, so as to get a deeper sense of the nature of their work. When they were asked to describe a typical day to illustrate the kinds of chores they do and the responsibilities they take on, I received the following response from Lungi:

³⁴ S – Single, M – Married

³⁵ Y - Yes, N – No.

³⁶ HIV + indicates that the voluntary caregiver lives with the Human Immunodeficiency Virus in the body.

³⁷ The dash (-) indicates that the HIV status is unknown. The decision to disclose HIV status was voluntary during the interviews.

“Firstly, I do not fully understand what my other colleagues’ routine of chores looks like, but mine varies from home to home. For instance, I currently visit five families who appear on my list. The primary caregivers of the first three sick people on my list are actively involved in care, so basically my visits consist of taking records on the progress of the patient. My fourth patient stays alone with her grandmother who is too old to offer much assistance. Therefore, I usually spend about 5 hours a day in that family. “My duties in the home consist of washing and feeding the sick person, and administering medication.” On days when she is due to collect her medication, I accompany her to the local clinic.” The last sick person on my list is bedridden with full-blown AIDS, making him quite dependent at this stage. He stays with his 10-year old son who attends school during the day. “I always see my role in this home as that of allowing the man’s son to experience as much freedom and love that other children of his age are accustomed to.” Unfortunately, I am unable to be with them early in the morning because I have other families to attend to. This means that he should prepare his sick father’s breakfast while preparing his in the morning. However, I always ensure that when the son gets back from school at about 14H00, I am there to sit with his father while he enjoys playing with the other children in the neighbourhood. I usually leave their home at about 16H00 after having washed the sick man and prepared supper for them, using whatever little resources they have. When I get home to my family, I cook dinner for them, bathe my two sons, wash the dishes and iron some clothes for my husband”.

In 2005, Lungi further explained:

“Prior to my part-time job at the clinic, I used to work 5-days a week in sick people’s homes. However, I now visit sick people on Monday, Tuesday, and Thursday. I use Wednesdays and Fridays to carry the duties of the clinic. The clinic expects me to prepare and submit a statistical report on the number of sick people visited every Friday. Our AIDS organization expects all voluntary caregivers to have under their care, a minimum of 5 and a maximum of 8 sick people in one month. I must admit that the work is challenging”.

Having listened to the stories of all ten women voluntary caregivers describing their typical day in CHBC, I was able to conclude that they do not perform similar roles and functions in the various homes. As reflected above, the nature of duties to be performed is influenced by the identified need in each individual home. These differences were also observed in starting time and finishing time on each day. Some voluntary caregivers began their work earlier than others, as Nonjabulo noted:

“My day begins at 7H00, the reason being that I am currently helping in a home where a single mother of three (3) children is very ill. The children are between the ages of 7 and 10 years. My daily duties include bathing and feeding the sick person on arrival, cleaning the house, and end my duties in that particular home by preparing food for the sick woman”.

She quickly added,

“...unfortunately, soon after completing those duties, I have to move on to my other homes. So, the children are always compelled to help their ill mother when they return from school – no matter how young they are!”

If all the different kind of chores/tasks can be grouped under different headings, chapter 4 might look as follows (see Diagram 1):

Diagram 1: Illustration of the progression of the disease

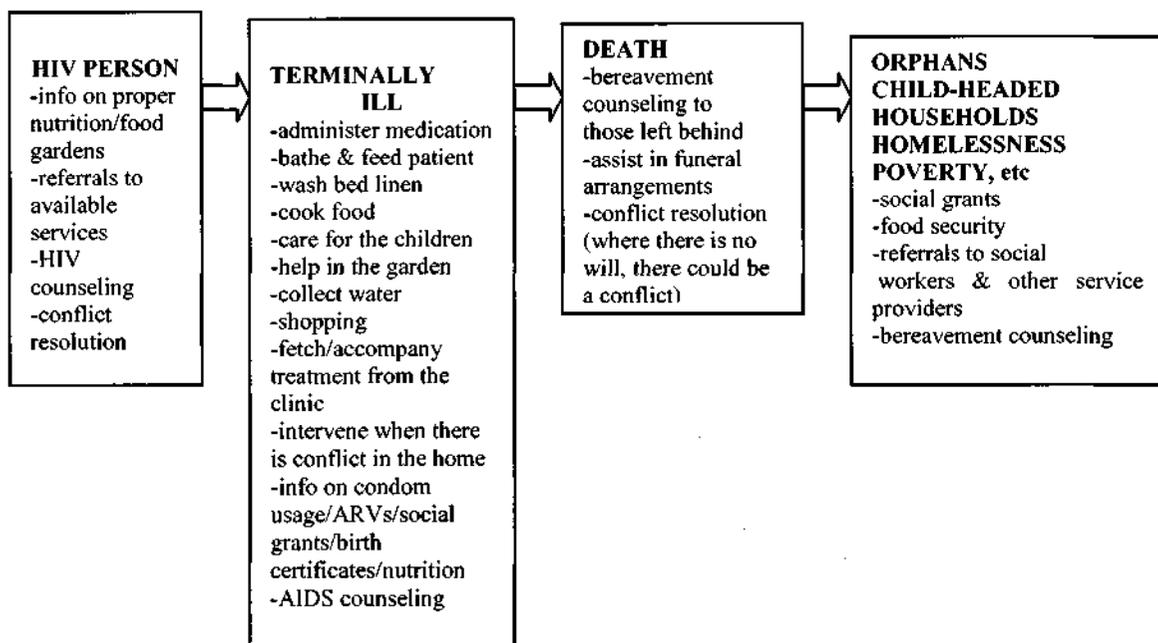


Diagram 1 shows that that the responsibilities of caregivers do not end when their patients die, but continues. I therefore argue that there is a need for the CHBC training to consider these realities.

According to the four women interviewed who are now in formal employment, their duties entail checking on patients who are about to embark on an ARV treatment programme, especially to investigate their living conditions. In order to measure a patient's readiness to embark on an ARV treatment programme, the voluntary caregivers need to verify if there is a mentor at home who could ensure that the patient adheres to the ARV treatment. This obviously requires the patient to disclose his or her AIDS status to at least one family member. Again, patients should neither be smokers nor alcohol drinkers if they want to access treatment. They should also practice safe sex³⁸, so as to contain the rate of infection and refrain from re-infecting themselves and others.

The voluntary caregivers reported that the process of identifying potential patients to be on ARV treatment programme begins when individual patients attend the Communicable Diseases Clinic (CDC) for a Voluntary Counseling and Testing (VCT). Should a person test HIV positive, they then need to do a CD4 count³⁹. A CD4 count of less than 200 indicates, according to the government criteria, that a person is ready for ARV treatment. Once those who have been identified as potentially ready for treatment, they are encouraged to attend classes on ARV treatment held at the clinic. The classes take a maximum of three weeks. It is at this point that the now employed caregivers come in, they then need to assist the professional health care staff to assess the local homes of the people who have already been identified. To begin the ARV treatment, the potential ARV participants should meet the criteria already outlined earlier. However, Lungi observes that, "some

³⁸ A commonly used prevention method in South Africa is a male condom usage. Female condoms are not easily accessible, while male condoms are distributed freely in public places (hospitals, schools, sport centers, churches, public toilets, shopping centres, etc)

³⁹ This is a measure of the strength of the immune system. HIV continually kills CD4 cells. Over time, the body cannot replace these lost CD4 cells and their number declines. When this happens the body will be more susceptible to infections. A normal CD4 count is 1000. The body starts to get more frequent common infections at around a count of 400. Around a count of 200 CD4, the body becomes susceptible to many infections (depts.washington.edu/madclin/patients/glossary.html)

patients wait for as long as eight months to commence their ARV treatment because there are many people on the waiting list.”

4 out of the 10 voluntary caregivers who have recently become part of this programme informed me that they are expected to report the home visits to the clinic every Friday. They earn a total salary of R600 a month for the work that they are doing.

The discussion that follows provides the context in which voluntary caregivers operate.

Poverty and hunger

All the voluntary caregivers interviewed alluded to the challenges and frustrations of caring in the face of extreme poverty. They mentioned that they predominantly visit poor families, where members *“never know where their next meal will come from”*. In such instances, some caregivers have felt compelled to use whatever personal resources they have to temporarily alleviate the poverty experienced in needy families. As Smangele explained:

“At my home, my father has a beautiful garden full of nutritious vegetables. He (my father) grows vegetables for his market in order to look after our family – and that is our only source of income. However, at times I am forced to take vegetables from my father’s garden to give to needy families that I visit in the local community”.

Lindi added her observation:

“It is such a pity that the PLWHA are sent home to die because many of them come from poor families. The one thing I like about hospital care is that patients are certain that three meals will be provided each day, whereas that is a luxury that poor families cannot afford”.

Similarly, Buyi observed,

“...for example, once a month we take food parcels to our patients’ homes, while I also wish I could take a parcel home for my family”.

It is in this context that Phumzile mentioned a need for CHBC trainers to clarify what is meant by volunteerism in the context of poverty as she could be heard saying,

“The training is silent on the need to reward the services of voluntary caregivers. We were taught the importance of personal hygiene in our CHBC training, but I cannot afford a perfume, I visit patients’ homes smelling of armpits due to the long distances I walk. I therefore see a need for the training to unpack what does a volunteer mean in our context”.

In order to illustrate the high degree of poverty, Nokuthula described the following incident:

“I visit poor people who are always hungry, only to find that at times I visit them hungry myself... I visited a lady who was HIV positive – the virus in her body had not progressed into AIDS yet. The lady was struggling to breastfeed her four-month old daughter, because there was not enough breast milk to feed the baby. I watched in sadness as the baby cried uncontrollably due to hunger and frustration caused by a lack of milk in the mother’s breast. A quick glance around the house told me that the mother has not had any food, and that is why she is failing to produce adequate breast milk for the baby. I thought to myself, Oh, my God, I have not been prepared for this situation...”

While reflecting on the challenges posed by poverty and hunger, Zanele commented:

“...without assistance from the government, community caregivers are literally scratching the surface. No matter how enthusiastic and passionate a voluntary caregiver might be about helping communities, one soon realizes that one cannot go far without outside support”.

A CHBC Coordinator expressed similar sentiments as Zanele. He identified a major source of stress among caregivers as emanating from the fact that they are expected to help sick and poor families without any support from the government and external development agencies:

“Can you really expect volunteers who go for days without food to become effective caregivers, particularly in contexts where some of them are infected themselves? Why is it that every time policy makers talk of volunteers in the

HIV AND AIDS scenario, they would expect poor people to play a pivotal role, while letting the rich and the GVT off the hook once again?”

These submissions were supported by most of the voluntary caregivers who keep hoping that some day they could get paid for the services they provide, as Sibusisiwe said:

“At home, nobody appreciates my involvement with the community, especially my mother who always says that my voluntary work does not put food on the table”.

Having noted that the daily hardships related to poverty and hunger does not challenge voluntary caregivers alone, but it affects their patients as well, Sibongile who now works for the local clinic in the ARV programme remarked:

“...people fail to take ARV drugs on an empty stomach ...having being recently exposed to the work at the clinic, we have been shocked by what we have witnessed there. There are some people who literally cry after testing HIV negative. They go to the VCT hoping and praying to test HIV positive so that they can also secure a government grant”.

Similarly, Lungi, who has also become involved at the CDC clinic, had this to say in relation to the problem of social grants:

“PLWHA who have a CD4 count of less than 200 are able to secure a care dependency grant of R700 from the government. Therefore, people who test HIV positive wait for the day when they could get this grant because it is mostly poor people who are hard hit by the impact of the disease”.

They further told me that some terminally ill people who are already on the ARV treatment programme stop taking their medication because they do not want to be taken off the social grant system. Apparently, people on ARV treatment are expected to check their CD4 count every six months. Once the CD4 count results show an improvement in terms of the number of healthy cells above 200 as a result of using ARV treatment, the government takes such patients off the programme. Therefore, according to the voluntary caregivers who also work for the clinic, this has resulted in sick people becoming reluctant to use ARV drugs because they want to keep their

CD4 count below 200. As Lungi noted, *"they depend on the dependency grant of R700 to support their families"*.

The need for employment

9 out of the 10 respondents indicated that they would leave voluntary work should opportunities of employment arise. As a result of the lack of opportunities, the volunteers often hoped that voluntary work would provide the necessary experience, which in turn would lead to remuneration that would enable them to improve their own livelihoods.

It is worth noting that almost all the community caregivers interviewed highlighted the lack of payment in the practice of CHBC as the major source of stress. As Dudu mentioned:

"I know that we volunteered to do this work, but many times we visit poor people who are always hungry, sometimes we visit them hungry ourselves and that leads to lack of motivation on our part".

When asked to describe an incident that was difficult for them, many respondents repeatedly echoed similar views to those given above as patients expect them to provide for their material needs such as food. They explained the misery and pain observed in various homes where the members of the family are all jobless. These difficult and demanding situations leave caregivers overwhelmed by feelings of inadequacy, anger, hopelessness, depression, deep sadness and grief.

Emotional needs

The respondents shared related sources of stress, which usually result from the challenges already outlined above. This includes working in a poverty-stricken environment, having to deal with their situation, particularly for those who are infected and affected by HIV and AIDS, stigma and discrimination, the nature and conditions of their work, etc.

Interestingly, when the voluntary caregivers were asked how they cope with stress, six of those interviewed could not understand the exact meaning of the question. Zandile responded by saying, *“I do nothing, and later I become okay”*.

Similarly, Dudu said:

“I would get home stressed and keep blaming myself. I would start beating the children and get angry with my husband for no apparent reason. But now it helps to attend prayer meetings in my church”.

The emphasis on confidentiality was identified as one other major cause of stress in caregivers. During the observations in the training, one participant who was already caring for a sick person who refuses to disclose to the family highlighted how the burden of care was weighing heavily on her:

“...because I am the only person the patient trusts, even her relatives and friends do not know about her HIV status – I am the only person that the patient has disclosed to...”

Nokuthula, on the other hand, described how she is always overwhelmed by guilt feelings when she is not present to help the patient.

“There are days when I would spend nights in my patient’s home, leaving my own children behind with my mother”.

The need to tackle stigma and discrimination

Despite many efforts established nationally to fight stigma and discrimination, this study has shown that many communities are still confronted with high levels of stigma, and the area of Mpophomeni where the study was conducted is no exception. Due to this reality, it was noted when the study was conducted that the voluntary caregivers who were infected had not yet disclosed their HIV status to the community nor to their peers within the CHBC programme. However, the CHBC Coordinator belonging to CHBC AIDS organization in the study revealed that many of them find it easier to disclose to their own clients, since they readily identify with their inner struggles and pains. According to the CHBC Coordinator, such voluntary caregivers

want to offer hope to the PLWHA they care for, by showing them that it is possible to live positively with the virus.

At the same time, half of the voluntary caregivers acknowledged that they were too afraid to go for HIV testing. Such revelations came as a huge surprise to me as this pointed to the stark reality of fear and stigmatization as the breeding ground for HIV and AIDS. Asked about similar experiences of HIV and AIDS stigma in the community, the voluntary caregivers who work for the local clinic on the ARV treatment programme - Sibongile, Sibusisiwe, and Lungi - made the following comment regarding some of the observation during home visits:

“When the local clinic sends us on field visits to assess patients’ readiness for ARVs, some of the patients never want to see us. They deny having a relationship with the local clinic”.

The problem of the high level of stigma in the community was further demonstrated when 2 out of the 10 voluntary caregivers expressed how the local people are always curious to find out how and where the sick person died. The overriding perception is that PLWHA are not admitted in hospitals, but are sent home to die. As one voluntary caregiver puts it:

“In our community, local people want to know whether the terminally ill person finally died at home or in hospital. If the person died at home, they assume that the ill person was infected with AIDS and could not be admitted in hospital... this sad reality perpetuates stigma against people living with AIDS, thus making the tasks of the community caregivers difficult”.

According to the voluntary caregivers interviewed, there is also a perception that those who offer care benefit from the organizations they are associated with. It was established that in some cases where the level of stigma is still prevalent, caregivers have been given various ‘labels’, such as being stigmatized as being infected themselves. Regardless of these unfounded allegations, caregivers are still motivated to assist their communities.

The majority of respondents acknowledged the significant contribution of home-based care, while Nonjabulo, Buyi and Zandile quickly added:

“Especially because people living with HIV and AIDS are no longer admitted in public hospitals – you only stay in a hospital if you can afford medical aid, therefore, there needs to be caregivers available to offer help.”

The need for professional support and effective networks

Asked about the causes of lack of motivation, three (3) voluntary caregivers shared their frustration at the poor service delivery at public clinics and hospitals. According to them, even public servants such as social workers are not always readily available and accessible to offer services. Zandile noted:

“When I visit a patient’s home, the PLWHA expect me to possess at least basic information on the different social grants, voluntary counseling and testing (VCT), etc. Many PLWHA have learnt that a referral is a sure way to get rid of them because such referral systems are flawed in that they do not respond instantly to the immediate needs of PLWHA and their families”.

This, according to Zandile, puts a lot of pressure and stress on them as caregivers, because,

“All we want is to improve the lives of our patients. To effectively fulfill that purpose, PLWHA must have confidence in the kind of service we provide”.

8 out of the 10 caregivers interviewed also reported that the great challenge in the area of home-based care is a lack of equipment, for example, home-based care kit. According to them, this leaves them vulnerable to infections. Nokuthula remarked:

“While we have been trained in the importance of taking the necessary precautions when caring for someone infected with AIDS, what do you do when there are no gloves and other important necessities?”

Further questioning revealed that Nokuthula strongly believed that ultimately quality care to PLWHA could be guaranteed only when the caregivers are given adequate care and support, because according to her, “...not much support and care has been given to caregivers”.

4.4 BACKGROUND TO THE CHBC TRAINING

The CHBC training organization is based in Pietermaritzburg and it plays a key role in CHBC training in the area. This organization forms part of a consortium of approximately 43 HIV/AIDS organizations in the region operating under the auspices of the Children in Distress (CINDI) Network⁴⁰. The consortium promotes networking and collaboration among the different stakeholders to avoid competition and duplication of services, since their mission is to foster a spirit of *Ubuntu*⁴¹. Therefore, the CHBC training organization as a partner of CINDI provides CHBC training for the different partner organizations who need such training. The strategic collaboration between the CHBC training organization and the AIDS organization in Mphohmeni, which are both investigated in this study, resulted from this collaboration within the CINDI network. Accordingly, the voluntary caregivers who participated in the study were recruited from within the CINDI structures, since potential voluntary caregivers who lack skills in CHBC are immediately recruited into the training shortly after joining the AIDS organization.

4.5 QUALIFICATIONS OF THE CHBC TRAINERS^a

Four different people, who took specific sessions on each day, facilitated the training under investigation. Bongwiwe, Zanele, and Nomonde focused on the daily facilitation of the course, while Sizwe only came in to facilitate demonstrations on the tippy-tap⁴³. Three of the trainers who participated in the study have a matric (Grade 12), and one trainer completed formal schooling at Grade 11. After completing formal schooling, they all pursued and attained other qualifications, and that includes qualifications for both formal⁴⁴ and non-formal⁴⁵ education. As illustrated in Table 3 below, I had an

⁴⁰ CINDI's vision is to be a multi-sectoral, well-resourced network of civil society and government agencies, capable of implementing diverse, effective, sustainable care and preventive HIV and AIDS programmes (Best practice series no. 2, 2000: 2).

⁴¹ Available [online] www.allaboutjazz.com/php/article.php A Zulu word, literally meaning "humanness." Ubuntu is a social and spiritual philosophy serving as a framework for African society. Its essential meaning can be conveyed using the Zulu maxim "umuntu ungununtu ngabantu" – meaning, in essence, "a person is a person through other persons." The practice of ubuntu is fundamentally inclusive, involving respect and concern for one's family and one's neighbours. It also implies respect for one's ancestors, in a deeper spiritual sense.

⁴² All the trainers' real names have been changed to protect their identities.

⁴³ See description below under course content

⁴⁴ This is a formal kind of education with a set syllabus and sometimes with prescribed books. Learners are prepared for formal examinations or assessment, and are awarded with formal certificates, diplomas or degrees. The certificates, diplomas, and degrees awarded to learners are mostly nationally recognized.

opportunity to interview four CHBC trainers working for the same CHBC training organization. All four CHBC trainers are Zulu-speakers and it emerged during the interviews that the CHBC training is only conducted in Zulu. The following trainers were interviewed: Bongiwe, Sizwe, Zanele, and Nomonde.

Bongiwe⁴⁶

Bongiwe is 55 year old, with two children and four grandchildren. She has a nursing diploma, which she obtained in 1980 from Montebello Nursing College. She began working as a nurse at Edendale Hospital in 1981. In 1997, after 16 years of experience as a nurse in a public hospital, she left the institution to join the hospice of South Africa. Reflecting on the experience, she said:

“...working in a hospital was the most stressful experience for me. This was due to operating in an environment where there is low morale among health care staff due to unfavorable working conditions: long working hours, low pay, overcrowded hospital wards, shortages in medication, etc. Despite all this, I still had a deep need to help sick people. I honestly felt called to the work that I was doing at Edendale Hospital at the time. While in search of a new employment where I could fully exercise and fulfill my calling to help sick people, a friend of mine told me about the Hospice Association of South Africa, and that is when my journey began”.

Bongiwe started at the hospice as a nurse for the sick. According to her, the work she was doing for the patients brought much fulfillment. She later moved to the CHBC training division, and began spending a great deal of her time in training members of the community in CHBC. This exposed her to a whole new world since the hospice had a relationship with the community, a relationship that the hospital did not have. At that point, she became interested to pursue other educational needs, so as to empower herself. She completed a course in HIV and AIDS counseling provided by

⁴⁵ This type of education is organized outside the established formal education. Like formal education, this kind of education has rules and regulations for enrolment, assessment, curriculum, etc but learners who participate in this type of education do not get formal qualifications. Only the providing institution normally recognizes the qualifications or certificates given to learners after completing their studies. Non-formal education, seen in this way, is part of a continuum between formal and informal education. The latter defined as learning from daily experience.

⁴⁶ When I conducted the last interviews in July 2005, I learnt that Bongiwe has left the CHBC training organization to work for another employer.

Lifeline, and also a course in community home-based care provided by the Sinosizo Home-based care. Other short courses that Bogie attended included a seminar in presentation skills, Lifeline's personal growth course, and writing skills.

Sizwe

Sizwe is 33 years old and married with a two-year old son. He is the only male involved in the CHBC training of voluntary caregivers in the organization under investigation. He completed Grade 12 from one of the local high schools in Pietermaritzburg in 1989. Asked about how he got involved in the CHBC training, he responded that he had been unemployed and stayed at home for 10 years. He decided to volunteer his time and skills to the CHBC training that formally employed him after working for a year as a volunteer. Sizwe had this to say about volunteerism:

“...talking from experience, I can tell you that a life of a volunteer is not easy. I had stayed at home for almost 10 years without earning a salary, and I could not wait to experience how it is like to gain financial independence”.

He added:

“If I were to be honest, I find it difficult to reconcile with the concept of volunteerism in my CHBC trainings. Maybe this is because I fully understand the socio-economic situation that certain individuals come from, and since I have undergone a similar experience of living for many years without a job, I know how difficult it is to work as a volunteer when your own basic needs have not been met”.

Given his views on the issue of volunteerism, I followed up on how he reconciles with the idea that the women who form a large majority of their CHBC trainings are expected to volunteer their services. Also asked about how the training considers the needs and rights of voluntary caregivers, he responded by saying:

“There is very little offered in terms of the needs of caregivers during the CHBC training. The organizations that bring potential voluntary caregivers to us expect them to complete the training and go into communities to assist PLWHA and their families. When we measure our impact, we quantify it by

reflecting on the number of voluntary caregivers who have begun working in the community after receiving training”.

In terms of further training after completing Grade 12, Simon has received mainly short courses of less than six months, consisting of training in community home-based care for trainers, HIV and AIDS counseling, auxiliary health care work, and public speaking.

Zanele⁴⁷

Zanele has a Bachelor of Social Science degree from the University of Durban-Westville⁴⁸, which she obtained in 1996. After completing her bachelor degree, she decided to work in the development field for the non-governmental sector organizations for the period of 5 years. As a qualified social worker, Zanele came into contact with the CHBC training organization while processing social grants for children referred to her by the beneficiaries of the training. She developed an interest in that area of work, since according to her:

“A large part of my work as a social worker basically consisted of administrative tasks. I did not know this during my training as a social worker, I always thought that I would be out there with the people in the community. But I soon realized that almost 90% of my time was taken up in processing grants, which consists of administrative tasks”.

Due to her experience and qualifications, she managed to get a job as a senior CHBC trainer in the CHBC organization. During the interview, Zanele soon realized how little she knew about community development:

“Before starting work as a CHBC trainer, I thought I knew everything about community work, particularly as a trained social worker. However, I realized that the training I had received as a social worker had not prepared me for the work I was doing. It never prepared me to deal effectively with so much poverty and misery that we witness everyday in our training participants”.

⁴⁷ When I conducted the last interviews in July 2005, I learnt that Zanele has also left the CHBC training organization to work for another employer.

⁴⁸ In 2004, the former University of Durban-Westville and the former University of Natal merged to form one University. The University is now called the University of KwaZulu-Natal (UKZN).

Zanele concluded that:

“The shortcomings in my social work training could be attributed to the lack of community development component in our training as social workers in the past. I understand that now the University has made it compulsory for all social workers to be trained in community development”.

While talking to Zanele, I noticed that she is a very reflective person. It therefore came as no surprise when she told me that to deal with stress, she usually takes a weekend away to some peaceful place for a reflective moment. According to her, the organization does not have adequate resources to organize weekends away for staff members, but she is always happy to use her financial resources for this purpose. She added: *“it is worth it otherwise one could die from burnout.”*

She has received training in community home-based care, which was followed by a training of trainers in CHBC, then HIV and AIDS counseling, time management, leadership course, and a one-year course in human resources management.

Nomonde⁴⁹

During the interview with Nomonde in 2003, I observed that she was very passionate about the work she was doing as a CHBC trainer. I soon discovered that before joining the CHBC training organization she had been working voluntarily in her local community providing CHBC to those who were ill at home. She told me how she became involved in the early days of the CHBC training, *“we were the first group to pilot the course in 1998.”* Having identified a need for a Zulu CHBC training course, they wanted to fill a gap which existed at the time, since according to her:

“The people who were attending the training course in huge numbers were mainly Zulu-speaking women, but the majority of the CHBC trainings were conducted in English. Back in 1998, we were not aware of any CHBC training conducted in Zulu in the Pietermaritzburg area”.

According to Nomonde, she was approached by the CHBC training organization, which needed volunteers to facilitate CHBC trainings in Zulu. The training

⁴⁹ When I conducted the last interviews in July 2005, I was informed that Nomonde passed away in 2004. May her soul rest in peace.

organization had already spotted her achievements in her community, and they presupposed she could be available to resume CHBC training duties with proper training when accessible. She reported that she “*grabbed the opportunity with both hands*”. She proudly stated how the experience has allowed her to grow as a person:

“I used to be very judgmental of people living with HIV and AIDS, but my involvement in the CHBC training taught me that I did not have to. I had an opportunity during trainings to listen to people’s stories that drove me to tears. I had to deal with my attitudes towards PLWHA, empowered in the knowledge that not all PLWHA are promiscuous”.

When Nomonde was asked how she achieved this positive attitude towards PLWHA, she responded by saying:

“Some people assume that as CHBC trainers we have all the knowledge and skills needed to do this work, but it is not the case. My change of attitude towards PLWHA came as I listened to people’s stories during the trainings. Some of the women who attend our trainings are infected and affected by HIV and AIDS. Most of these women have always been loyal to their spouses, but they still contract the virus. What is that telling us about HIV and AIDS? I suppose for me, every time I come across women in that similar situation during CHBC trainings, it becomes a constant reminder of women’s vulnerabilities”.

In terms of previous training to prepare Nomonde in her training role, she was offered short courses of less than six months, that is, training in community home-based care, HIV and AIDS counseling, bereavement counseling, child and youth care, and training on social grants.

Table 3: Age, sex, experience in CHBC, and qualifications of the CHBC trainers

TRAINER’S NAME	AGE	SEX (M/F) ⁵⁰	CHBC YEARS OF EXPERIENCE	HIGHEST QUALIFICATION
BONGIWE	55	F	8	Diploma in nursing
SIZWE	33	M	5	Grade 12
ZANELE	34	F	4	B. Soc. Sc.
NOMONDE	58	F	7	Grade 11

⁵⁰ M – Male, F –Female

4.6 FORMAT OF THE TRAINING

The CHBC training that I observed took place from 28 July to 1 August 2003. The course is run over five days comprising eight hours on each day. Each session began at 8H30 in the morning and finished at 16H30 in the afternoon. On each day, tea was served at 10H00, and lunch at 13H00. The training included 18 participants between the ages of 22 and 60. IsiZulu was used as the medium of communication during the training, since all women participants were Zulu-speakers. At the training, two participants brought along their babies, one was 3 months old and the other, 4 years old. These women had no one to leave their babies with. All training participants had to travel to the training venue each morning, which was right in the city center, with easy access to public transport. A free CHBC training was provided, since the organization where caregivers volunteer their services cover both the training and travel costs. The venue was quite spacious and this provided adequate room for group activities, such as role-plays.

4.7 COURSE CONTENT AND FACILITATION PROCESS

The ultimate aim of CHBC provision at community/home level is to ensure proper and quality care to people living with HIV and AIDS. However, the different interviews conducted with voluntary caregivers and also CHBC trainers at various intervals clearly demonstrated different understandings of what is meant by quality care, even though this term is overly used in the field of CHBC. The CHBC trainers were asked to comment about the measurement tools used to assess the quality of care provided in the home. All four CHBC trainers who were interviewed outlined it as fulfilling the following responsibilities:

- Supervise and administer medication
- Educate and support families
- Bathe and feed patients
- Help patient's mobility
- Accompany patients to clinics/hospitals
- Keep records, etc

The role of voluntary caregivers as perceived by the trainers, is also reflected in the CHBC training course content. The course content of the CHBC training organization that was observed covered the following sessions.

DAY ONE

The training participants had to sign an attendance register, and this register had to be signed each morning as a tool to monitor the level of attendance. Each participant also received a 60-page course manual. The manual was very user-friendly and easy to read and follow instructions with the use of cartoons to illustrate and emphasize certain points.

The first day of the training began with a welcome and introduction of everyone present. In introducing themselves, the CHBC trainers mentioned the brief history of their organization and also outlined its vision and mission. The participants were encouraged to adopt a similar approach by including the names of the NGOs that they volunteer their services to. Having attended to the details on housekeeping, the trainer facilitated an icebreaker aimed at helping participants to know and understand each other better. It was interesting to observe the high level of participation and cooperation between both trainers and participants, with all involved fully engaged in the process. What followed was a session whereby participants had to list their expectations in buzz groups while the trainer captured the ideas on a flipchart. What was observed from the responses given was an overriding expectation of a need to be capacitated with adequate skills and knowledge to make them effective caregivers.

I observed with interest how the topic on home-based care fitted in nicely when it was finally introduced because of the relevant activities conducted prior to its presentation to the participants. The trainer posed a question on what is home-based care. The main objective of the question was to examine the participants' understanding and knowledge of home-based care. In concluding this session, the facilitator explained that as an organization they do not only focus on people living with HIV and AIDS (PLWHA) in their home visits, but they always encourage participants to attend to the different needs of people who are house bound. According to them, that includes the physically challenged, and the elderly people.

After a 30min tea break, participants were placed in groups. In their groups, participants were given a task to reflect and discuss what they deemed as necessary qualities of a good home-based caregiver. The facilitator encouraged them to select a scribe and someone to report back on behalf of the group. Having spent about 45min in group discussions, each group was given an opportunity to report back. It was realized that all groups had covered almost similar qualities such as cleanliness, neatness, patience, sympathy, listening, respect for others, non-judgmentalism, love, ability to offer hope in a hopeless situation, spiritual person, compassion, observant, trustworthy, ability to keep confidentiality, healthy self-esteem, knowledge and skills. In reflecting on these qualities, the facilitator encouraged all participants to look within themselves and begin to work on their individual shortcomings and weaknesses, which could possibly hinder their creativity and productivity while offering care in various homes.

Regarding the quality of respect for others, the trainer emphasized the need for caregivers to be conscious and sensitive to the rights of the patients. The rights of the patients, as outlined in the course manual, includes access to the following rights:

- Fair and equal treatment
- Freedom to be themselves – caregivers to avoid comparisons
- Freedom to make their own choices
- Offer themselves hope
- Make decisions regarding their health condition
- Freedom of expression, no matter how different the views are
- Access to medical attention for pain relief
- Access assistance from family members
- Be offered care by compassionate people who understand the patients' needs

A discussion ensued soon after the trainer's input on the rights of patients. One participant struggled with the relevance of confidentiality, particularly around HIV and AIDS, and she shared this observation:

“I visit sick people in the community who have not disclosed their HIV status to family members. I carry a heavy burden because that places an unnecessary

burden and demand on my shoulders to be always available for my patients, whereas the idea behind CHBC is to empower the patient and family so that they collaborate in providing care within a home-setting. What can we do to deal with stigma and discrimination against PLWHA and assist them to break the cycle of silence?”

Instead of encouraging an open discussion on the issue, the CHBC trainer expressed her opinion in the following words:

“Unfortunately, as caregivers you need to recognize and respect sick people’s rights for privacy. Should you disclose your patients’ HIV status without their permission, they have a right to take you to the court of law”.

Prior to breaking for lunch, the facilitator gave a lecture on infection control which focused on the need and ways to deal with germs in the household, personal hygiene which specifically dealt with the need for the caregiver to ensure personal cleanliness and neatness at all times, and finally environmental hygiene. In conducting a session on the latter, the facilitator handed out two separate teaching sheets containing illustrations of two separate houses. The two teaching sheets were different in that one has dirty grounds, creating a very unhealthy environment, while the other one has everything in good condition thus promoting and creating a healthy environment. The participants had to compare and decide on what needed to change in the dirty house. This kind of exercise worked exceptionally well in that while participants worked individually, it kept them excited and attentive to what they were doing. The facilitator thereafter encouraged and welcomed responses from the participants’ observations and notes.

After a 1hr lunch break, the trainer concluded the discussion on environmental hygiene. To end the day’s work, participants were encouraged to provide verbal feedback to evaluate the programme. A few outspoken participants expressed their gratitude to the facilitators, and highlighted how they had enjoyed the training on that very first day. The day was closed in prayer.

DAY TWO

The second day opened with a gospel hymn, followed by a spontaneous prayer from one of the participants. I soon noticed that there was no arranged seating pattern in the learning environment, participants chose places where they felt comfortable. The day's schedule began with a topic on nutrition. Having outlined the need for good nutrition to ensure a patient's well-being, the facilitator asked the participants to brainstorm a list of food that contains protein. The responses included meat, fish, cheese, milk, eggs, beans, peas, lentils, and peanuts. When asked about the food that contains vitamins and minerals, the participants suggested the following items: cabbage, broccoli, spinach, carrots, butternut, oranges, bananas, apples, pears, avocado, and onions. In outlining a list of food that assists patients to restore their strength and energy, the participants outlined the following: bread, potatoes, mealies, samp, rice, porridge, wheatbix, oats, and cornflakes.

A demonstration followed on how to prepare an oral rehydration solution, which helps to prevent dehydration in patients suffering from diarrhoea. Demonstrations are useful for teaching participants procedures. It is a very effective method of instruction, particularly as it provides participants with the opportunity to repeat procedures. A recipe of the rehydration solution was written on a flipchart, and the facilitator used that information to demonstrate to the entire group on how they could make their own solutions. Participants who were interested were encouraged to taste the rehydration solution afterwards, which according to them, had a nice taste similar to that of a glucose mixture. In a follow up on what could be done to alleviate pain and discomfort of patients, other home remedies, such as a sour fig⁵¹ were mentioned. According to the facilitator, a sour fig is found lying close to water streams and along the sea. It is effective as a treatment of sores and thrush all over the body.

After a 30min tea break, participants were taught about home visit etiquette, which they found helpful. The trainer at that point mentioned the need for caregivers to always keep records when they visit patients' homes. Those records are used for their weekly reports and they were informed that the reports need to be detailed. When

⁵¹ species *Carpobrotus Edulis*

asked to reflect on what needs to be observed when approaching a patient's home for the first time, the participants listed the following needs:

- To affectionately greet family members
- To introduce oneself outlining the nature of one's work and purpose of the visit
- To provide an opportunity for the family member to introduce themselves
- To be patient and wait for the family to share about their loved one who is ill
- To assure family members of confidentiality
- To wait patiently for the family to check with the sick if he/she wants to be in a company of a caregiver
- To ask for permission to make notes so as to remember what is being said
- To provide the family with your contact details before leaving their home
- To finally offer hope

Six participants then volunteered to conduct role-plays to illustrate in practice what had already been presented. In role-playing, participants adopt characters, or parts, that have personalities, motivations, and backgrounds from their own. In this context, participants were actors who were practicing the use of authentic language and appropriate behaviour of the local community. When the participants were asked to role-play home visit etiquette, the exercise drew attention to some of the practical challenges involved in caring for sick people in the home.

In a role-play that was conducted during CHBC training, participants were asked to imagine themselves as parents living with a terminally ill daughter. They then receive a visit from a voluntary caregiver who has come to offer free services.

Scenario 1

In the first role-play, the mother challenges the voluntary caregiver demanding to know who informed her of her sick daughter. This unexpected response presented a difficult situation for the voluntary caregiver who had come to provide home care. Consequently, the voluntary caregiver had to leave the house not having had an opportunity to meet the patient who was lying in the bedroom. This particular role-play offered a real, daily challenge that voluntary caregivers are confronted with,

however the observations revealed that the trainer was not adequately prepared to deal effectively with some of the concrete issues that surfaced during the role-plays. She responded by saying:

“The mother has been very difficult in this instance, and can we request a mother from the second role-play who is willing to cooperate with the voluntary caregiver”.

Scenario 2

In the second scenario, even though the voluntary caregiver was granted permission to meet with the sick daughter, the scene posed challenges of a different nature. Since the participants had already been taught the importance of respecting the rights of patients, the mother was good in checking with her daughter if she wanted any visitors before allowing a stranger inside the house. The daughter responded by asking if the visitor was bringing any food with her. Although this unfortunately was not the case, the visitor was welcomed in. During the informal conversation with the voluntary caregiver, the sick daughter mentioned a need for HIV testing to ascertain the cause of her illness. In this scenario, the voluntary caregiver could not offer any encouragement and information available in terms of voluntary HIV counseling and testing (VCT) sites, she could only be heard saying, *“it is a good idea to go for an HIV test.”* The mother then objected to this idea, suggesting that their neighbour had bewitched her daughter. Once again, such misconceptions, and the implications thereof, which are so prevalent in the HIV and AIDS dilemma were left unchallenged by the trainers and other participants. Due to her mother’s remarks, the sick daughter was left feeling misunderstood and alone in her distress because of the mother’s ill informed views.

The next session consisted of a presentation on ways used to assist the patient with mobility and transfers. The trainer used a lecture method to explain the crucial role of a caregiver in assisting the patient with bodily movements. According to the trainer, this act helps to offer some kind of physical exercise for the patient, thus restoring strength. The session also touched on the need to transfer and re-arrange certain things in the household so as to keep everything within the patient’s reach.

After lunch, the afternoon session began with a topic on nursing care symptoms, followed by issues on HIV and AIDS, record keeping and the session concluded with an evaluation of the day's work. The presentation on HIV and AIDS supplied a definition on what is meant by HIV and AIDS, outlined the three modes of transmission, that is, sexual intercourse, infected blood, and mother-to-child transmission, promotion of safer sex through condom use, being faithful to one partner, information sharing, and use safe precautions when touching bodily fluids. The session on HIV and AIDS went further to offer ideas on creating a supportive environment for PLWHA, that is, taking care of their emotional (love), spiritual (faith), social (friendship), and physical (exercise and relaxation) needs.

Before ending the day's programme, the trainer outlined key elements of a patient's record that is well kept. She stressed the fundamental need for caregivers to focus on detail. In using an example, she emphasized a need for facilitators to be observant and use all five senses during home visits, that is, sight, hearing, smell, touch, and taste. According to the trainer, patient's records should cover all the necessary details such as detailed information on the patient's health and living conditions, including any support provided by other community groups and individuals. The participants were finally given homework on record keeping, and they were expected to present their reports the following day. The day's programme ended with an evaluation and closed with a prayer.

DAY THREE

On the third day the session opened with songs and a prayer. It was clear that had become normal practice. From 9H00 to 11H00, the participants spent time presenting their reports to the entire group on record keeping. The task was for each participant to imagine herself caring for a terminally ill patient, and then describe observations for the attention of the CHBC supervisor. This was one of the most interesting sessions, as one listened to stories of the women caregivers using their imaginations to describe settings, events, and health conditions of their visualized patients. What struck me most was the fact that most of the stories sounded so real, and very touching. Clearly, they were informed by experience.

The entire afternoon was spent on practicalities on pressure care, mouth care – and after lunch bed bath. Pressure care focuses on relieving pain caused by long periods of sleep, which sometimes results in bed sores. The participants were invited to consider some of the ways that could be used to prevent bed sores, which included helping them to turn to avoid lying on one side for long hours, putting pillows and cushions to protect body joints, or taking the patient outside the house. In dealing with mouth care, the trainer lectured on the different ways of doing this and that includes cleaning the mouth using either a bicarbonate of soda or ordinary salt to gargle in order to prevent mouth sores from developing, also encourage patients to avoid using too many spices, and only eat light meals and take cold drinks.

Finally, the session focused on a step-by-step demonstration on how to bed bath a patient. The participants were shown how to take off the patient's clothes, with minimal discomfort and pain. They were further shown what to do when the patient has soiled the clothes. The session also involved demonstration of different positions to be used in turning the patients' body around, brushing the patient's teeth, dressing the patient, etc.

The day concluded with all participants providing a verbal evaluation on how they had either benefited or not benefited from the day's schedule. All participants closed the day by saying a prayer.

DAY FOUR

The fourth day opened in prayer. The content of the training entailed a topic on caring for children, loss and change, how to educate adults, impact of sickness in the home, organizing wills/ funeral policies, a practical on how participants can make their own temporary water-taps to be used in desperate situations where no taps exist, and this temporary tap is called "a tippy tap" in the context of their CHBC course. The course content further comprises a list of referrals and other available resources, and finally the evaluation of the day's programme.

The first topic, which covered the needs of children and ways to care for them, began by focusing on the impact of HIV and AIDS on children. When the participants were

encouraged to reflect on the negative consequences of the pandemic, the responses given included the growing need to care for orphans and vulnerable children (OVC), and also children in child-headed homes (CHH). In terms of care for the OVC and CHH, participants focused specifically on the needs to ensure that best care is provided holistically, that is, taking care of their emotional, economic, social, safety and security needs. Conditions likely to leave children vulnerable to danger and threat were highlighted as including lack of parental guidance, which leaves children vulnerable to sexual, physical, and emotional abuse. The session also looked at caring for children living with HIV. According to the input given by the trainer, children need to know places where they could access social services, including psychological assistance, and also medical attention under the supervision of an adult. They need to be provided with nutritious food and kept away from emotional pain and worry to avoid stress. The session further looked at the South African Schools Act no 84 of 1996, which stipulates that it is the right of every child to have access to education. The information provided further highlighted those eligible to be exempted from paying school fees, and that included foster and adopted children whose parents/guardians are unable to pay school fees. The trainer also elaborated on the procedure that needed to be followed in applying for exemption of fees.

After a tea break, the trainer asked the participants to reflect on what they regard as examples of changes brought about by loss and change in people's lives. The participants were given a few minutes to think individually, and thereafter the responses were provided and included the following: sickness, conflict, death, birth of a child, problems in personal and intimate relationships, accidents, buying a new house or car. All participants acknowledged that the changes that take place affect the entire family and those close to them. In reflecting on the different emotions as an outcome of such changes, the participants outlined such emotions as anger, fear, regret, self-blame, sadness, grief, and loneliness. The following techniques were cited as some of the ways used in dealing with emotions during loss and change:

- Expressing one's feelings (it's okay to cry!)
- Finding a person to talk to
- Talking to God through prayer
- Writing down your feelings in a journal

- Keeping oneself busy through physical exercise
- Spending quality time reflecting on what makes one happy
- Using relaxation techniques, and finally taking one step at a time.

Following a session on loss and change was a topic on how to educate adults. As soon as I recognized that the content also dealt with a topic on teaching adults, I patiently waited to hear exactly what that entailed. Unlike what I had imagined, the topic paid attention specifically to the list of things that caregivers need to consider when teaching family members to take care of their loved ones who are ill. The underlying principle in home-based care is for family members to learn to do things for themselves thus becoming independent of the caregiver. Therefore, the primary focus of this session on educating adults dealt purposely with the transfer of knowledge from caregivers to family members without necessarily considering principles on how adults learn. The session further looked at the impact of sickness in the home, with particular focus on the loss of household income when a breadwinner is ill.

After lunch, the day's programme focused on linking caregivers to available resources in the community and highlighting the fundamental role of caregivers in referring communities to the right places where they can possibly access social services. The section on referrals and available resources in the community was followed by demonstrations on making a tippy-tap. The trainer demonstrated all the steps and procedures involved in making their own tippy-tap. According to CHBC trainers, such taps become useful in rural areas where taps are scarce. Using a 2L plastic juice container, and a thread, the CHBC trainer demonstrated how participants could creatively make their own taps. Training participants were also given an opportunity to repeat the procedures during a 'hands-on' practice session. This helped to reinforce the learning process. By immediately correcting the participants' mistakes and reinforcing proper procedures, the trainer effectively and efficiently helped the participants to learn the tasks more quickly. The participants were expected to make their own tippy taps the following day. The programme ended with an evaluation of the day. The workshop closed in prayer.

DAY FIVE

The day opened in prayer. The day's programme began with the tippy tap presentations constructed by the participants. The trainer called for five volunteers to make their own tippy taps so as to demonstrate their understanding. This went exceptionally well.

What followed after the tippy tap presentations was a session on wills and funeral policies. The trainer asked the participants to work in groups⁵² to discuss the necessity of wills and funeral policies. During the report back, the participants stated the essential need for family members to draw their wills and also invest in funeral policies. According to them, such planning assists in avoiding unnecessary conflict in homes after loved ones have died. In a situation where one dies having not had such a plan in place, those left behind were likely to suffer, particularly the orphans.

What followed after the morning tea was a session on the process of death and dying. The participants spontaneously shared their experiences of caring for a family member who had been ill, without necessarily mentioning the cause of illness. In all cases, those reported ill eventually succumbed to death. I observed with interest how the facilitator missed opportunities of further learning from the participants' experiences at that particular moment, which could have been used to explore emotions associated with care for the terminally ill people. The impact of this failure to build on prior experience of the caregivers will be explored in detail in the next chapter. Instead the facilitator gave a lecture on the known symptoms in sick people who are about to die, and that included: frequently fast asleep, change in breathing, too much saliva in the mouth, coughing, experience difficulty to swallow, mild loss of sight, loss of memory and a loss of a sense of time, place and sequence of events. The trainer went further to provide the main strategies to be employed during that difficult time. The list included the following needs:

- To pray for the dying
- To begin planning the future of the children to be left behind

⁵² Followed a similar approach in putting participants in groups as earlier described in initial group work sessions. See DAY ONE.

- To encourage family members to discuss the will, funeral policies, and special funeral arrangements should the person die
- To keep all necessary documents in a safe place
- To spend 24 hrs a day by the bedside of the patient. During that time, all those around the terminally ill person need to communicate and gently lay a hand on the person.

According to the input given by the facilitator, all the needs of the dying outlined above need to be provided by the immediate family members, relatives and friends with assistance from the voluntary caregiver. The following needs, according to the course content, are to be provided by community members:

- To assist families to take care of orphans
- To financially support needy families
- To offer support and required assistance following the funeral
- To respond to any other need that arises from the family of the deceased.

The analysis of findings in chapter 5 highlights the potential danger for such programmes that rely on assumptions that the community would be readily and willingly available to offer help.

While still on the issue of death and dying, one participant asked about the appropriate approaches needed to address the sensitive issues surrounding the process of death and dying. The trainer emphasized a need to constantly offer hope to PLWHA and their families. She further stressed the importance of doing this even when the situation seems hopeless. The CHBC trainer was heard saying:

“We need to constantly remind ourselves as caregivers of our fundamental role, which is to bring peace, joy, and comfort to the PLWHA and their families. Even when confronted with a situation where you know the person living with AIDS is dying, you need to provide ongoing hope and support. There is a need for caregivers to see themselves as vessels of love and hope”.

The final session on that Friday afternoon briefly dealt with a topic on caring for caregivers. Having had this session after lunch on the last day of the training, it did

not receive the priority it deserved, as can be imagined. The trainer only listed the points that caregivers need to observe in caring for themselves. This was done single-handedly without engaging the participants. The four points that were outlined as needs for caregivers in caring for themselves were as follows:

- To maintain a healthy diet
- To make time for relaxation with family
- To join other community support groups for debriefing
- To create time for spiritual reflection and prayer
- To pursue other personal interests outside of care

The implications related to the tendency to overlook the needs of caregivers are explored in detail in Chapter 5.

Following the trainer's presentation on the care for caregivers, the trainers hurried into handing out evaluation forms to be filled in. However, four of the participants asked to be excused as they had made other appointments for the same afternoon. The rest of the participants were given a few minutes to complete the evaluation form. The questions on the evaluation form allowed the participants to comment on the venue, meals, facilitation, and training programme. When the trainers were asked how they were going to constructively use the feedback from the participants, I was told that it helps to inform their future planning so that they successfully address the different needs. Finally, participants were awarded with certificates of attendance.

At a glance, it is not difficult to make general conclusions about the CHBC training content, which appears to offer basic skills in nursing care at home. As reflected above, the content is concerned about the physical well being of the patient, therefore, the voluntary caregiver is given skills in preparing home remedies, dealing with infection control, bed bathing, prepare O.R.S, etc. A large part of the training content is patient-centred, and the two sessions that tend to consider and prioritize the needs of the caregiver do not reflect in practice what the content claims.

In this section, an attempt has been made to highlight what the course content in CHBC offers. The next section is critical in the sense that it looks at the teaching methods employed during the training.

4.8 CAREGIVERS' PERCEPTIONS OF THE CHBC TRAINING CONTENT

This section comprises what worked for the participants and what didn't as related to the CHBC training. Generally, the voluntary caregivers were appreciative of the CHBC training that was offered. It was revealed that some of them enjoyed certain sessions of the training better than others. As Dudu made the following comment regarding skills offered on home visit etiquette, which was the most useful thing she learnt on the course:

“It is very important to gain skills on home visiting because one needs to understand that families have different cultures and beliefs, and as voluntary caregivers we need to be sensitive and consider these realities when we approach people's homes. Coming from the African background, I always assumed that it is expected to offer prayers during visits at the home of the sick, but one time a family member reprimanded me for praying having not sought permission”.

She further added:

“Having learnt these skills on visit etiquette has really enhanced my manner of approach during home visits. It has truly worked exceptionally well for me”.

All 10 voluntary caregivers interviewed were generally pleased with the methods used during the CHBC training. 3 out of the 10 voluntary caregivers reflected on the role-plays and how they enjoyed acting the scenes out in the learning environment, as Buyi noted: “*we used to laugh our lungs out.*” According to the caregivers, the role-plays were effective in raising issues from the local context, as Lindi puts it, “*issues that were real for us.*”

However, while praising the training overall, there were also criticisms. These pertain particularly to the failure of trainers to deal with difficult issues confronting CHBC

volunteers in their daily work, to acknowledge and build on existing experience and knowledge, to focus on the needs of the caregivers themselves, to provide counseling skills, and to close the gap between the daily practice of caregiving and the training offered.

Smangele and Sibusisiwe felt that the key issues that emerged from the role-plays were not effectively addressed, for example, problems associated with stigma and discrimination, poverty, and hunger.

Similarly, Smangele expressed the following concern:

“During the debriefing session following the role-plays, I raised personal issues affecting me. I felt that the CHBC trainers were not prepared to deal with it. I am actually not too sure whether they were caught unprepared by the issues I raised, or this was maybe due to the lack of methods to deal with the situation”.

7 out of the 10 voluntary caregivers reported that they enjoyed learning by doing. They therefore shared how much pleasure they got from following instructions during demonstrations, for example, bathing and brushing the ill person’s teeth. However, one voluntary caregiver reflected on an exercise they were asked to complete as a group and felt that the groups were not always well structured and monitored. She said:

“Some training participants were too domineering and nothing was done to deal with the situation. There were participants in my group who never had a chance to speak and articulate their thoughts, because some people were just too strong and vocal for them”.

During the interviews, 8 of the 10 participants indicated that they had already been involved in CHBC prior to the training, caring for relatives, friends, and neighbours who were living with HIV and AIDS. However, Sibusisiwe who had lost a sister to AIDS in 2001 and who is living with HIV remarked:

“There was no attempt made during the training to draw lessons from my own experiences. I honestly felt that the training was not providing any

opportunities for me to deal with the struggles and pain in my own personal life”.

Due to these challenges Zandile lamented:

“I wish the training could also focus on my own needs as a volunteer. My observation is that the training assumes that my personal needs have been met, and that I have so much to offer. Ultimately, the focus is on the sick person’s needs and not mine. I was told that a helper is not supposed to cry, but one time I did”.

Looking back on the CHBC training, the following comment seems to sum up a feeling shared by all voluntary caregivers trained in community home-based care:

“...being part of the training made me to slowly realize that the concept of home-based care is not a new idea, but something I have been doing all my life. I did not know that I was already doing it, but now I know....”

4.9 GAPS BETWEEN PRACTICE AND TRAINING

Skills and knowledge of caregivers

When asked about the skills and knowledge one needs in order to provide home-based care, 8 out of the 10 voluntary caregivers indicated that when at the patients’ homes, they are expected to make multiple decisions to ensure the best quality of care. Smangele cited the fact that in the patients’ homes, a caregiver needs to be a *‘jack-of-all-trades,’* a view which challenges the dominant narrow view employed in defining the tasks of CHBC in ensuring quality care to PLWHA and their families. When pressed for an answer in terms of specific skills and knowledge needed, 2 out of the 10 voluntary caregivers reported that:

“Firstly, a caregiver needs patience. We are actually taught at the training course about the need for patience, perseverance, and humility. Otherwise, if a caregiver does not have these important qualities, she will not be able to exercise tolerance under difficult circumstances in the various homes”.

She further added:

“A caregiver needs to be a good communicator, because talking is what we do more than anything else. To be an effective caregiver, one also needs to have

skills in conflict management, particularly because of the dynamics experienced in homes as a result of a positive HIV test and impact of illness. There is also a need to understand where the different government resources are located and how these could be accessed. People in the homes want to find out how they could get birth certificates for the children so as to access social grants. They are also in need of information on the different social grants, especially on who is eligible for such grants. I also personally feel that caregivers need training in managing diversity. The reason being that I am Christian, and I always find it difficult to assist a sick person of a different faith”.

The findings revealed that only 5 out of the 10 voluntary caregivers interviewed possessed CHBC and counseling skills (see Table A). 3 of the 10 caregivers only possess skills in CHBC with the exception of counseling. One of the voluntary caregivers who has participated in both trainings lamented:

“I fail to understand how those of us who are not trained in counseling cope in people’s home, because most of what we do is communication. I even learnt that I do not always need to take decisions for those I care for. Prior to my training in counseling, I used to decide when I will be taking my patients to the clinic, but now I always verify with them if that is what they would like to do. CHBC puts more emphasis on the sick, while counseling on the other hand focuses on caregivers as well, helping them to build their skills and competencies in dealing with their own and other people’s feelings”.

According to Anne, a counseling trainer at McCord’s Hospital in Durban who was also interviewed in the study, the danger of having CHBC voluntary caregivers untrained in counseling is that they tend to give advise or tell families and PLWHA what to do:

“They easily create a power position, which is disempowering and allows neither the patient nor their families an opportunity to express their feelings and limitations. It is, therefore, vital to help home-based care workers understand their own motivation, objectives, strengths and weaknesses through the provision of counseling tools”.

She went on to say that normally the community caregivers' actions are based on the fear of their own incompetence, "*you are never quite a nurse*", or fear of being rejected by a patient or family members. Asked what she would foresee as challenges facing voluntary caregivers in the home-setting who are not trained in counseling, the response was as follows:

“...to resort to an advisory role...to carry the entire load on your own, and not refer PLWHA to relevant resources. To sympathize and be nothing more than a helpful neighbour...to easily give up and be discouraged. To become bitter as you try hard and people not wanting to do it your way. To provide information that might not be relevant to the particular patient and to work with outdated information”.

In considering the CHBC training, she further added:

“We were trained for four years as nursing sisters and counselors, how come that community caregivers nowadays undergo a five-day training then are deemed adequate and readily available to provide holistic care in a home setting? Who will place confidence in such care?”

The women who were interviewed for the purposes of this study indicated that the members of their group who had counseling skills received their training elsewhere, as it was never provided as part of the CHBC training they attended. They were not even aware of an organization in their area that could offer training in both as part of the comprehensive package. However, the voluntary caregivers who have been trained in counseling acknowledged the role and impact of the training on their own lives. As outlined in the Lifeline Personal Growth Manual (1999), the benefits of counseling comprise the following:

- To provide an opportunity for deeper self-awareness for group members to explore, by way of a guided visualization, specific aspects of themselves, thus allowing them to reflect on their learning to date.
- To help participants to reflect on their past and see how it relates to the present.
- To provide members an opportunity to risk deeper self-disclosure.
- To allow for an opportunity for group members to express, discuss and cry over painful memories of loss.

- Awareness of journey of personal growth to date, the dropping of masks, forming, building and maintaining of new relationships.
- To draw attention to different styles of dealing with anger and conflict.
- To promote awareness of own prejudices and to resolve to make efforts to change.
- Communication skills, including listening, etc

When asked about the gaps regarding the practice and provision of CHBC training, 6 out of the 10 caregivers cited the need to consider making counseling part and parcel of CHBC training. Lungi mentioned a need for CHBC providers to also organize workshops with a different focus for voluntary caregivers to assist them in paying attention to other interests outside of care.

- HIV and AIDS, particularly its impact and ARV therapy
- A course on dealing with stress and trauma
- A course on conflict resolution

The ARV rollout programme was announced in 2003, and the implementation of this programme started at pilot sites in 2004. It is now reported that the programme is implemented nationally in all public hospitals. This has posed new challenges to the work of voluntary caregivers. As Nokuthula mentioned:

“I think those of us who were trained prior to the ARV rollout programme need further training to keep ourselves updated. In my situation, for instance, I do not fully understand what ARVs are all about and how they operate in the body. I feel that I need this information, because some of the people in the home that I visit want to know”.

When requested to think about the challenges in the homes that are not reflected in the training, Zandile responded by saying:

“I feel there is a huge gap between theory and practice on the ground. I recall that we were taught the purpose of CHBC which is to teach the family to take care of their loved ones. However, the training did not prepare me for the many homes where I arrive to find there is no family structure, only a sick

person lying on the bed. I can never begin to tell you how dehumanizing it is to bathe a man of my father's age".

Similarly, Dudu asked:

"In cases where family members are not available to learn the skills from us, we feel compelled to carry out the duties of a caregiver, especially to offer the basic nursing care. But again what would be our role if family members were to fulfill all the roles and responsibilities of a caregiver?"

4.10 CONCLUSION

This chapter presented the findings using patterns and themes emerging from the stories of women and other key informants interviewed. It outlined the profiles of women caregivers by focusing on who they are, where they come from, what motivates them, what prior experience they had and what kind of training they have received to prepare them for the caregiving role. The study further reflected on the working environment in which caregivers operate, and this was done by looking at a typical day in the life of a woman volunteer. In outlining the needs of caregivers, the study findings highlighted a need to alleviate poverty and hunger, a need for employment, emotional support, to eradicate stigma and discrimination, a need for professional support and effective networks, and finally a need for further training. The discussion concluded with an outline of voluntary caregivers' perceptions of the CHBC training.

The next chapter shall endeavor to discuss and analyse the findings.

CHAPTER 5

ANALYSIS OF FINDINGS

5.1 INTRODUCTION

This chapter analyses and discusses the findings of the study in relation to the purpose and the objectives as outlined in chapter 1. The study aimed to explore the content of a CHBC training organization designed for voluntary caregivers and compare this with the working reality. The aim was to determine whether the CHBC training would adequately prepare women voluntary caregivers for the work they do in community home-based care given the psycho-socio, economic and cultural environment of this work.

The discussion focuses on the underlying assumptions in community home-based care (CHBC) in the light of the profiles of women voluntary caregivers interviewed. This will be followed by an examination of the CHBC training curriculum in order to identify the strengths and gaps in CHBC training. Finally, this chapter will focus on the challenges facing CHBC trainers as facilitators of the learning designed for adults.

5.2 UNDERLYING PRINCIPLES IN CHBC

Community care is the best place for quality care

Despite the tremendous challenges posed by HIV and AIDS, it is claimed that the community seems to be the best place where patients could be afforded quality care. Hospitals do not have the personnel and resources to cope with the huge demands that HIV and AIDS make on them, and they are too expensive. CHBC is therefore seen as the most empowering tool for both PLWHAs and their caregivers working in the community.

However, as shown in the previous chapter, the findings clearly indicated that the demands placed on voluntary caregivers are too formidable to cope with because most of them work in poverty-stricken communities. Graham (1991 cited in Williams,

1997) observes that women are principal caregivers in CHBC, however, the majority of voluntary caregivers are poor themselves. Consequently, a number of authors in the literature review cautioned against the assumption that communities, particularly women caregivers, are willing and committed to provide care, because as noted in Barnett & Whiteside (2002) such commitment can become overshadowed by poverty and related socio-economic difficulties.

Moreover, the environment is not conducive to community care, as the study indicated a high level of stigma and a lack of access to technical and professional support. Using Tallis & Cavanagh (2005) for my analysis on the issue of power, I argue that it is an illusion to assume that CHBC empowers voluntary caregivers since the findings have demonstrated a lack of access to power and resources. Added to this, is the fact that the CHBC curriculum is silent on the needs of voluntary caregivers.

A cost-effective model of care: who benefits?

The National Guideline on Community Home-based Care (2001: 8) acknowledges that it is poor families and poor communities that are hardest hit by the impact of HIV and AIDS. The guidelines still maintain that the rationale for CHBC includes involving communities in care so as “to reduce costs” associated with institutionalized care; reduce the pressure on hospital beds and other resources at different levels of service; and prevent the need for expensive institutional care. However, listening to the plight of volunteer caregivers, it was evident that they do not benefit much from such arrangements. The question that needs to be explored further therefore, is who benefits from these savings?

The study has shown that most caregivers work in isolation in private homes; thus, the impact of caregiving is concealed. The provision and practice of CHBC perceived in this way, supports the ideas of privatization, where the burden of care has been shifted to poor communities. To elaborate the link between privatization and CHBC, it needs to be recognized that privatization is the outcome of globalization, which according to Barnett & Whiteside, (2002: 352) puts “the market as the arbiter of welfare”. In this context, it calls for a minimization of the role of the state, because the concern is on

economic growth at the expense of growing inequality. In simple terms, privatization helps a few rich people to become even richer, while the majority needs of the poor are ignored and overlooked. As it stands, the burden of care has been shifted to poor communities, and no platform has been created for the caregivers to articulate their needs.

The government needs to revisit and rethink its macro-economic policy, which encourages a cut in public expenditure on social services such as health (The NUMSA Shopsteward Publication, 2002). Privatization, which is the result of such interventions, continues to widen the gap between poor and rich people – between the have's and the have not's - and leaves poor people vulnerable to diseases such as HIV and AIDS which thrive in poor countries and within poor communities. While wealthier people have options, that is, they can choose to be treated in private hospitals and die in the care of professional staff if they want to, 'poor'⁵³ people do not have choices. So, is community home-based care a specific option for the poor?

Do communities and families themselves perceive CHBC as a benefit as reflected in CHBC model, or as a liability to accommodate those who have been chased away from the hospitals? The literature review given suggests that staying in hospital nowadays is a privilege for the 'rich', while the 'poor' can die at home. At this stage, it is befitting to consider Freire's ideas on the importance of acquiring a critical consciousness about the contradictions in society. I argue that there is a need to link CHBC training with training in consciousness-raising, that is, while learning new information on care for the terminally ill, such information could be linked to the socioeconomic context, thus generating awareness about social, economic, and political contradictions in participants' lives. Radical and popular education practitioners maintain that the goal of adult education programmes should not be to fit participants into the needs of capitalist societies, as the government's macroeconomic policies such as the Growth, Employment and Redistribution (GEAR)⁵⁴ suggest, but

⁵³ Poverty means different things to different people. In this particular context, the term 'poor' refers to people who lack access to basic social services such as electricity, water, food, and proper sanitation.

⁵⁴ A market-driven government strategy, with the government having a limited role in driving the reconstruction of the country. It is committed to a reduced expenditure on social services and new infrastructure, and set about privatizing state assets (Marie, 2004: 77)

to help participants develop the skills needed to control their own lives, make informed decisions and to work for social change.

5.3 THE POOR TENDING TO THE POOR

In the findings of the study, the profiles of the women interviewed revealed that it is mostly women who provide community home-based care. As was noted in earlier chapters, the CHBC organization under study has a total of 16 voluntary caregivers in their programme, and all of them are women. The profiles further showed that these women are black, and mainly poor or very poor. As indicated in Table A given in the previous chapter, the age group of the women interviewed ranges from 22 to 44. This reflects that the women who participated in the study do not fall within the bracket of school-going age, but within the working group. 7 of the 10 women interviewed indicated that it was due to a lack of financial resources that they left school before completing matric. When the initial interviews were conducted in 2003, further questioning related to employment history revealed that 8 out of the 10 voluntary caregivers had never been employed. The two women interviewed who had been employed in the past, reported that they worked as domestic workers after dropping out of school before completing Standard 10 (Grade 12). Follow-up interviews conducted in 2005 revealed that four of the women have been temporarily employed to assist at the local Communicable Diseases Clinic. One of the women, who worked as a domestic worker in the past, now works at the clinic. While the total number of women who have been in employment has increased to five since 2005 this is by no means representative of the majority of CHBC.

Working for free

The findings have shown that a number of women engage in community home-based care with the hope of acquiring experience that could lead to job opportunities. Due to the difficult environment in which the caregivers work, some of them have to visit hungry people while hungry themselves. The study revealed that for many of them, such hardships are bearable in the hope and knowledge that they might find employment in the future because of the experience they would have gained in doing CHBC work. Indeed, their hopes were founded on reality since four of them have now found employment. However, feminists critically recognize the tendency of

governments to relegate women to low-paid, part-time jobs. In the situation of the caregivers who are now employed, the work at the clinic is temporary and they are only paid R600 a month, which is only adequate to buy them cosmetics.

Barnett & Whiteside (2002) recognise that the policies on community care are attractive to politicians because they control the costs of care borne by the state, however they do not take into account the opportunity costs for women in terms of income lost. This also explains the reasons why the payment of stipends to women caregivers to compensate for loss of earnings has been a matter of some debate among policy makers. I argue that the issue of payment for voluntary services is a moral and ethical one in the face of dire poverty in South Africa. In cases where women's labour is not reimbursed financially, levels of motivation are affected negatively as it is demonstrated in caregivers in the study. It was reported in the previous chapter that the withdrawal of a stipend of R100 a month resulted in some of them losing interest in their work as voluntary caregivers. I therefore argue that policy makers, planners and other development workers need to consider some financial reward for caregivers and avoid romanticizing CHBC as the best model when it relies on cheap and free labour.

Privileging one set of needs over another

The study has demonstrated a tension between the needs of PLWHA and the needs of those who care for them. The tendency is to address the needs of the sick without recognizing those of caregivers. However, the study showed that many women voluntary caregivers are as needy as the beneficiaries of care. The study revealed that the duties of voluntary caregivers include encouraging PLWHA who are still not at the final stages of the disease to get involved in growing vegetables. The purpose is twofold: it is for PLWHA to feed themselves and their families and also to earn extra money by selling surplus produce. When an evaluation is done on the needs of PLWHA, service providers need to realize that some of their needs reflect those of their caregivers. Many volunteers are also poor, therefore, it would seem unethical to expect them to go to sick people's homes and help to grow their gardens, from which they could also benefit. This reality demonstrates one of the injustices that caregivers are confronted with. Their rights and needs are usually overlooked while the rights of

PLWHA and their families are taken into account. As one caregiver remarked that they take food parcels to the homes of the sick people, while she also wishes to take a parcel home. These observations make it clear that the needs and rights of the sick person in the field of CHBC seem to be considered more important than the needs and rights of the caregiver.

Surprisingly, the government continues to hold a strong belief that communities are capable of providing home-based care for the terminally ill. The former KZN Health Minister indicated in no uncertain terms that the fight against HIV and AIDS would not be won in the hospitals but in the community with home-based care (Leeman, 2003). However, there is a danger in assuming that communities and families are capable of providing care without assistance from the government. Often, people tend to blame themselves for the social ills that affect them, and for their failure in meeting set standards, in this case the objectives of CHBC. Conscientization aims at enabling people to make the connection between their personal actions and the wider cultural, economic and political context, as Brookfield (1987) has argued.

Caregiving as invisible labour

The study has clearly demonstrated the meaningful contribution that caregivers are making in society to alleviate the cost associated with caring for the terminally ill. However, as indicated in the study, their contribution to the fight against HIV and AIDS seems insignificant, ignored, and less appreciated. The current focus in the fight against HIV and AIDS is on scientific research, treatment, policies, etc – and the people who always get the credit are in such selected fields. However, the caregivers play a key role in service delivery at the local community, and without their effectiveness and availability there will be no implementation. Therefore, there is a need to ask whose work is valued and whose goes unrecognized? A challenge for policy makers, service providers and various stakeholders is to increase their support of volunteers by taking their needs seriously and give them the recognition they so rightly deserve.

Interestingly, regardless of the lack of recognition of caregivers in the public domain, the respondents in this study indicated that some of their motivation comes from the

fact that their contributions are acknowledged and appreciated in the local homes where they offer CHBC.

5.4 CHBC TRAINING CURRICULUM

Chapter 4 presented a CHBC training course, highlighting the content, format, teaching methods, and facilitation. This was a 5-day training that took place in Pietermaritzburg city centre, almost 30km from the community in which caregivers operate. The format of the training consisted of a programme that began at 8H30 on each day, and finished at 16H30. There was a tea break at 11H00 and lunch was served at 13H00 on each day. There were four trainers/facilitators who facilitated the training and they used the following methods: discussion, buzz groups, role-plays, and lectures. Having observed the 5-day training, there was no doubt in my mind that the participants had benefited from the training. This evidence is based on the constructive feedback given at the end of each day's programme. However, the study has highlighted gaps in the training.

Reflecting on the course content as demonstrated in chapter 4, the CHBC focuses more on the vocational training as the key aspect in caregiving. At a glance, the session on caring for caregivers appeared to be concerned about the needs and the rights of the caregivers, however, my observation is that the session did not receive adequate time since it took place after lunch on the last day. Moreover, it did not highlight the needs of voluntary caregivers by giving it the priority it deserves. One would have expected that the women were going to be given a platform to articulate their views, and begin organizing collectively for action.

Considering the qualifications and skills of CHBC trainers as outlined in chapter 4, it is evident that they possess some of the relevant skills and knowledge needed in their field of CHBC training. However, this section will show how the lack of other appropriate skills such as dealing with difficult issues confronting caregivers in their daily work, acknowledging and building on existing experience and knowledge, focusing on the needs of caregivers themselves, providing counseling, and linking the work practice and the training seem to threaten the quality of the training that is

offered. The discussion that follows affirms what went well and challenges what needs improvement in terms of the training.

The multi-faceted nature of care

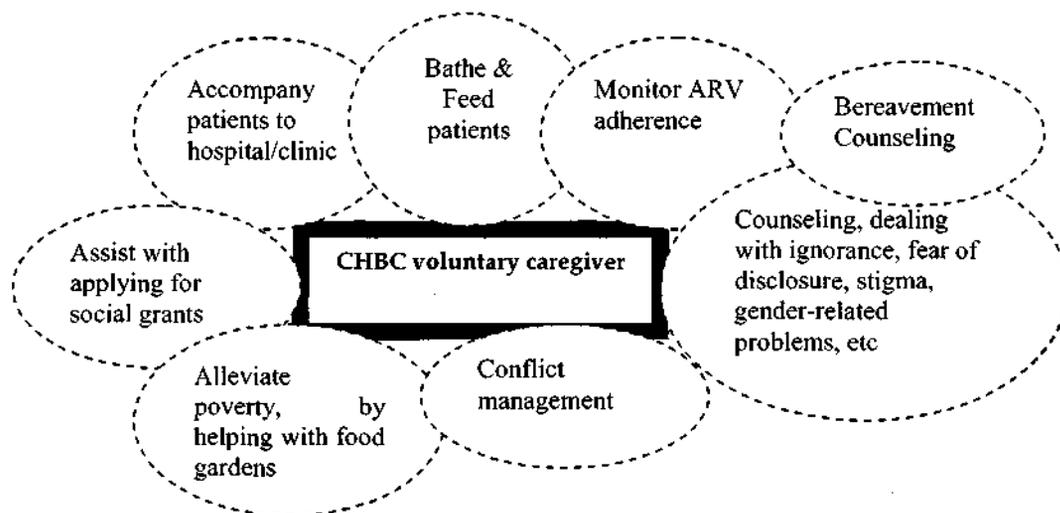
In chapter 2, the literature review has shown that the objectives of each training organization puts emphasis on offering a comprehensive package in terms of CHBC training provision, which includes the social, emotional, spiritual, and material needs of people living with HIV and AIDS. It has been demonstrated that this comprehensive package is only directed at helping the PLWHA and their families. Therefore, the emphasis on care for the needs of the sick tends to overlook the needs of the caregivers, thus bringing into question the claim that the CHBC training is comprehensive.

While the training focuses heavily on the practical aspects of care, the study findings have shown that caregiving is multi-faceted in nature. Again, even the practical training provided during the training was limited in the sense that the duties that the caregivers perform in the field of caregiving go beyond the content provided during the training. The evidence is shown in some caregivers who indicated that their role in some homes include assisting with shopping, cleaning the house, cooking, fetching medication for patients, caring for the children, etc. Due to this lack of pattern for all households, the study has shown that many voluntary caregivers are exposed to long hours of work. Even though the roles and responsibilities to be performed by the caregivers in various homes are outlined in the National Guideline on CHBC (2001), these are not practical in some instances. This problem could be attributed to the fact that the duties and roles of voluntary caregivers within a household are not properly defined. Therefore, caregivers become vulnerable to abuse and exploitation in the absence of government policies, which leave them vulnerable in the hands of both the CHBC organizations that they belong to and also the beneficiaries of care in the community.

Diagram 2 illustrates the duties that caregivers in the study perform in the different homes. The women caregivers, some of whom live with HIV as well, must make multiple decisions such as the following:

- Accompany patients to hospital/clinic
- Bathe and feed patients
- Monitor ARV adherence
- Provide HIV and AIDS counseling, including bereavement counseling
- Assist with applying for social grants
- Alleviate poverty by helping with food gardens
- Manage and resolve conflict within households

Diagram 2: highlights the multifaceted nature of roles and responsibilities



A need for training in HIV counseling as part of a comprehensive plan

The research findings identified sources of stress in voluntary caregivers who participated in the study. Some of the causes of stress in caregivers emanated from the tendency to personalize their patients' problems. Therefore, the challenge for service providers is to ensure that volunteers remain reflective, healthy and effective because it is in doing so that the quality of care could be assured.

As shown in chapter 4, when asked how they deal with stress, some caregivers failed to share their experiences, like one caregiver, Zandile (2003) who did not have any mechanism for dealing with stress, she simply 'does nothing and later becomes okay.' This could be interpreted as suggesting a situation where caregivers have never been

helped to deal with stress and also not offered adequate opportunities for self-reflection on positive and negative experiences emanating from their field of work. Similarly, another caregiver, Dudu (2003) shares how she carries the burden of care and, due to a lack of opportunity to de-brief, in turn becomes violent towards her children at home. According to her, she would arrive home stressed and keep blaming herself, beating the children up, and getting angry at her husband. I maintain that such behaviour highlights the need for counseling in CHBC, particularly among other things, to create an opportunity for self-reflection.

Counseling, according to Johnson (2000: 3 cited in van Dyk, 2001: 9)), is a structured conversation aimed at facilitating a client's quality of life in the face of adversity. The intention of counseling "is not to solve everything by prescribing treatment", but to help or assist clients to review their problems and options or the choices they have for dealing with these problems (Egan, 1998 cited in van Dyk, 2001: 10). Miller (2000: 89) observes that counseling was almost unheard of as a cornerstone approach to public health management in any field prior to the emergence of HIV and AIDS. Certain factors, however, such as lack of viable interventions for treatment, stigma and discrimination associated with HIV and AIDS, lack of government support, the shock of diagnosis, and recognition of the social impact of HIV diagnosis, had many groups of those most directly infected and affected, especially PLWHA and their families, in need for psychological support.

One voluntary caregiver, Nonjabulo (2003), who has been trained in counseling, shared her experience on the benefits of counseling. Having being trained in counseling, she strongly felt that the CHBC puts more emphasis on the needs and rights of the sick, while counseling focused on enhancing coping mechanisms in caregivers. This echoes Uys (2003: 7) who maintains that, "the tasks most often performed by caregivers are counseling and giving information (94% of visits), giving psychological and emotional support (45% of visits)". Based on this knowledge, it is therefore, vital to incorporate counseling among the most important skills a caregiver needs.

The study has shown that some caregivers are too scared to visit a VCT site for HIV testing, while others are afraid to disclose their status to others. This raises a major

concern because caregivers are expected to deal effectively with similar issues in various homes that they visit. Reflecting on the issue of caregivers who are infected and affected themselves, Gibson, Swartz & Sandenbergh (2002) use a number of case studies to illustrate the complicated issues of care in such contexts. Caregivers are overwhelmed by their own pain, feelings and memories, thus face the double burden of their own emotional pain and that of their PLWHA. Furthermore, Gibson et al (2002: 8) points out the danger in this, that caregivers find themselves compelled to try and make their patients feel 'better', in much the same way perhaps that they hoped to have got over their own emotional distress around these kinds of issues. In his analysis, counseling is outlined as a major instrument in dealing with many of these issues that people are confronted with.

The study showed that despite the demands involved in caring on a voluntary basis, there are volunteers who feel a sense of vocation to the kind of work that they are doing, therefore, they are willing to provide care for others. This is reflected in the experiences of one caregiver in the study, Sibongile, who is motivated to get involved in caring despite the practical demands. Gibson et al (2002) note that for some caregivers, this kind of work seems to satisfy a deep, personal need in addition to their more logistical aspirations. If so, voluntary caregivers could be referred to as "wounded healers" (Bartsch, K. & Bartsch, E, 1995: 149), that is, people who are driven to help others because of their own experiences of pain or difficulty. The voluntary caregivers interviewed in the study could be perceived in this way because the study revealed that a high percentage of them are infected and affected with AIDS as well.

However, as indicated earlier, a need for opportunities of debriefing need to be created, otherwise an overly close identification with patients' could overwhelm caregivers' capacity to be effective helpers. I therefore maintain that counseling could play a role in helping caregivers to deal with their emotions, and help them to prioritize their own needs.

A need to build on prior experience

In chapter 4, I provided examples of a situation whereby participants raised issues, which were not included in the course, but relevant in the participants' context. The trainers were unable to effectively respond to such arguments, as demonstrated on examples of the role-plays. In the first role-play as indicated in the previous chapter, a voluntary caregiver is denied access in a sick person's home. Not knowing what to do, the trainer quickly dismissed the group and invited a second group to come forward without dealing with the issue at hand. In so doing, the trainer failed to make use of the opportunity to address some of the key challenges in the practice of CHBC, which could have helped to deal with the rejection the caregivers sometimes face in some of the homes they visit. The training participants in this role-play performed without any hesitation. The issues raised in the role-play came naturally, and this could be attributed to the fact that the issues were real for them, meaning that they actually portrayed a challenge they have experienced in their own local context outside the formal learning environment. However, the CHBC trainer failed to deal adequately and creatively with the issues that surfaced.

In the context of a larger argument about the type of training that needs to be provided, I need to draw from the concepts of social learning. Some things could only be learnt on the job through situated learning, but what is needed is an opportunity to reflect critically and to offload emotionally. In achieving this, the role of facilitator becomes very critical. According to Aronowitz (1993: 15) learners should be engaged in a dialogue, focusing on "problem-posing as a basis of dialogical education" (Shor, 1993: 4). This Freirean approach is crucially directed to breaking the cycle of psychological oppression as it helps learners to confront their own lives. In this context, the main purpose would be to enable learners to articulate their own feelings, thus helping learners to examine deeper issues in society and begin to explore new ways of seeing the world. It is against this background that Freire (1993: xii) encourages educators to always tie their narratives of liberation to people's stories. In so doing, the approach recognizes the need of a pedagogy that begins with helping learners achieve a grasp of the concrete conditions of their lives, of the limits imposed by their situation on the truism 'knowledge is power.' This kind of education emphasizes 'reflection', in which the learner assimilates knowledge in accordance

with his/her own needs, progressive tradition to helping the learner become a subject of his/her own education rather than an object of the system's educational agenda.

The second role-play highlighted the need for caregivers to be informed and always on top of the issues. In failing to challenge the mother of a patient who was convinced that her daughter had been bewitched, the caregiver in the role play failed to address some of the common misconceptions in the field of HIV and AIDS. Maybe the facilitator could have created a platform for a lengthy discussion on the issues. Even though a discussion ensued after the role plays, it was quite superficial due to the trainer's insistence on offering hope under difficult situations. Lifeline Personal Growth Manual (1999: 12) warns against giving false hope and instead promotes a need for caregivers to acknowledge their own limitations by recognizing that one cannot have the answer to every problem while dealing with unique situations all the time. Therefore, individuals and groups involved in caregiving could only be effective if they listen more and talk less. In that way, helping people to work through their problems and finding solutions, which they could own.

As shown in chapter 4, even though there was a high level of participation during the training, the facilitator did not make use of the opportunity to build on the experiences of the learners. In learning from experience, Boud et al (1993: 2) suggest that it requires interaction with elements outside the learner, therefore, one could argue that the learning environment that the trainers had created provided ample opportunity for learners to engage in fruitful discussions regarding the issues, then create a platform for learning from each others' experiences. In terms of recognizing and building on prior experience, a conducive environment could have been possibly created for voluntary caregivers who are infected and affected to feel safe to disclose their experiences. Otherwise, it is of grave concern that caregivers who have been trained in CHBC are also victims of fear and stigma surrounding HIV and AIDS. The study findings revealed that for those reasons, some caregivers resort to non-disclosure. The question is: who will break the cycle of silence that is killing so many people? If people who have been trained in CHBC are still vulnerable to fear and stigma, what

about ordinary people who only read about awareness campaigns on billboards created by Lovelife⁵⁵?

In my view, the stigma and ignorance that surround the issue of HIV and AIDS is still the number one killer of people living with AIDS. As indicated in the reports of the three caregivers who work for the CDC, since the introduction of ARVs some people fail to access drugs in fear of being known to be HIV positive in their communities. Due to this reality, it is sad to note that people continue to die unnecessarily. My argument is that voluntary caregivers have the potential as agents of change, to transform the present reality. This can happen only when the CHBC ensures that the learning is situated, and building on people's realities.

5.5 CHALLENGES FACING CHBC TRAINING PROGRAMMES

Providing relevant and well-researched information

This is a challenge to ensure that the communities are capacitated to confront effectively the challenges posed by HIV and AIDS, and one way of doing this would be to ascertain that CHBC community caregivers are well trained and are working in a conducive and supportive environment. When Nkwe-Mabua (2000: 10) conducted a study on the effectiveness of CHBC, it was discovered that very little has been done to evaluate CHBC for people living with HIV and AIDS. As it is the case with the CHBC organization under investigation, the literature revealed that most CHBC programmes in developing countries are run by NGOs without any substantial contribution from the government.

Creating a career path

During the interviews conducted with community caregivers, findings revealed that some of the community caregivers have hopes and dreams for the future. Therefore, those working in training need to consider the personal long-term goals of caregivers

⁵⁵ South Africa's national HIV prevention programme for youth, which was launched in September 1999, by a consortium of leading South African public health organizations in partnership with a coalition of more than 100 community-based organizations, the South African government, major South African media groups and private foundations. Available [online] at: <http://www.kff.org/about/lovelife.cfm>

and begin to realize the importance of using the training to put them on a career path. During the review of various CHBC training manuals, which included a training manual of the CHBC of the organization in this study, it was observed that many CHBC courses are not accredited with the South African Qualifications Authority (SAQA).⁵⁶ Uys (2003: 12) cautions that exploiting voluntary caregivers' vulnerability is not to be commended. She goes further to say that the CHBC training invested in volunteers should give them additional skills and confidence, and in some instances, make them employable.

However, even though it might seem right for voluntary caregivers to grasp any opportunity for employment that comes their way, this arrangement is not always practical for many CHBC organizations in KZN who are expected, particularly by funding organizations, to deliver measurable results, and these organizations often work under financially constrained environments. Therefore, they find themselves trapped in positions with high expectations placed upon them, feeling the weight of responsibility without sufficient resources to perform the way they would wish. This simply means that a dropout in the number of voluntary caregivers who have moved to formal employment is not perceived as a success story. In the case of the CHBC under investigation, it was established while conducting this study that to retain their voluntary caregivers, they have initiated certain strategies such as withholding certificates presented after the course, until caregivers complete their 6 months practical component, which is now considered strictly as an important component in the course. It needs to be noted that this was not the arrangement in their former CHBC trainings, nevertheless as a result of voluntary caregivers turnover they considered this to be an appropriate response.

Offering further training

The study indicated that some of the CHBC trainers are unable to deal adequately with the challenges involved in the training of voluntary caregivers for people living with AIDS. Therefore, there is a need for re-training CHBC trainers, with emphasis

⁵⁶ The South African Qualifications Authority (SAQA) Act was passed in 1995. The Act brought the National Qualifications Framework (NQF) into being, with SAQA as the body responsible for developing and implementing the NQF. The NQF was created to drive a process of creating parity between academic and vocational learning, as well as between formal, non-formal, and informal learning (Allais: 2003)

on the adoption of adult education principles. As the study has shown, the participants in CHBC trainings are mainly adults, therefore, it is a basic necessity for trainers to have skills and/ or experience in basic adult education methodology. As all caregivers recognized that they have been doing home-based care all along without even knowing, *"I have been in caregiving all my life"*.

Unlike children, adults bring prior experience into the learning situation, and for this reason, adult education principles argue for a need to build on such experience, since adults do not learn in a vacuum, but bring their experiences from their social context into the learning environment. Post-modern feminists support this view as they proclaim that all identities are socially constructed and therefore the outcome of context-specific relationships (Hurtado, 1996). However, this does not mean that facilitators need to romanticize the experiences of adults without any critical engagement. Brookfield (1987: 37) stipulates that there is a need "to identify and challenge assumptions" to promote critical thinking and perspective transformation. This occurs when one becomes aware of and begins to question the habitual role or system of rules that he or she automatically follows in a given situation and begin to acknowledge that alternatives exist.

As mentioned in the study, during observation in the training, the CHBC trainer made no attempt to challenge some of the misconceptions presented by the training participants. As a result, the trainer failed to adequately address some of the key challenges prevalent in the field of HIV and AIDS, such as misinformation, ignorance, denial, stigma, and discrimination. A potential danger could be that while on the field of care, caregivers could perpetuate the existing misconceptions about HIV and AIDS. For example, when I accompanied one caregiver, Sibusisiwe, to visit one of her patients in the local community I observed the following: We found a terminally ill young man of about 35 years old. The man was with his parents, wife and children, when we arrived. He related a story of how he had been bewitched by colleagues at work who were jealous of him, thus bluntly denying the possibility of being infected with AIDS. The voluntary caregiver continuously offered unrealistic reassurance that things would get better, despite the fact that the PLWHA was actually dying without a proper diagnosis. Clearly it would have been most helpful to

the family, particularly the wife who was also present, for the voluntary caregiver to find out how the entire situation affected them, and listen with minimum interruption. Such attitude could have probably helped the family to express their anger and frustration and put them onto a path towards inner healing, and might have lead the wife to go for counseling and a test, herself. However, such an attitude could be attributed to the emphasis in the CHBC training placed on how voluntary caregivers should make PLWHA and families feel better, which then compels caregivers to be flattering and pleasing even in complex situations.

5.6 WORKING TOWARDS A COLLECTIVE SOCIAL ACTION AGENDA

I strongly believe that the caregivers are potential agents of change. In the field of CHBC, they are the hands and feet, eyes and ears of government, including researchers, policy-makers, and the organizations they work for. However, what is of concern is the fact that while the role of voluntary caregivers is acknowledged, policy-makers and development planners are not providing the necessary support for caregivers as shown in this study. As reflected in chapter 4, caregivers work under extreme circumstances, within environments that are characterized by poverty and hunger, unemployment, stigma and discrimination, slow delivery of ARVs. Therefore, there needs to be a recognition that HIV and AIDS is not simply a personal health issue but a social health and development one. If so, it is necessary to create conditions in which women can speak about their experiences. A feminist view maintains that, "each of us has the right to speak one's own voice and have a part in making decisions that affect one's life" (Pharr, 1988: 1 cited in Hooyman & Gonyea, 1995). It is such context that Tallis & Cavanagh (2004: 6) and Hooyman & Gonyea (1995: 33) would argue for a need to recognize that the "personal is political". In so doing, women's caregiving role needs to be moved from invisibility to visibility. As Hooyman & Gonyea (1995) further recognize, this is because within the feminist framework, the goal is to break down the dichotomies of public versus private domain. By naming and identifying what was previously silent and invisible through collective social processes, women voluntary caregivers in the CHBC could be able to influence policy- and decision- makers to acknowledge and value their significant contribution, thus providing more resources in support of caring.

My contention is that the CHBC training provides the best place to begin organizing for collective social action. The main objective could be allowing the voices of courageous ordinary women to be heard, whom according to Hurtado (1996), would not otherwise be heard, for collective good. This could only happen if the CHBC training adopts the feminists' views, as Aronson (1991 cited in Hooyman & Gonyea, 1995) maintains, that validating, listening to, understanding, and building on women's individual and collective experiences as caregivers is the first step in breaking the silence that surrounds the issues of caregiving and is the basis for changing the prevailing pattern of care. In this analysis, Bricker-Jenkins & Hooyman (1986: 29 cited in Hooyman & Gonyea, 1995) asserts that breaking the silence enables the discovery of a common ground and establishes publicly the uniqueness and diversity of women's experiences.

There is no doubt that it is a challenge for CHBC service providers, policy makers and other relevant stakeholders to "allow people to make connections", by providing the kind of education that leads to enlightenment and development of liberated adults, instead of domesticating learners by creating "cultures of silence", in which according to Freire (1970: 22) the body carries out orders from above. In such situations, thinking is difficult, and speaking the word is forbidden. To work towards liberation of learners could mean creating opportunities of reflection during the learning process. There is a need for both learners and practitioners to confront power within the practice of CHBC – who has the power to decide and "whose reality counts"? (Chambers, 1997: 100). Ultimately, my dream is for CHBC educators to produce liberated, instead of domesticated learners, who are critical analysts and knowing adults from the learning environments in which they produce.

5.7 CONCLUSION

This chapter presented the analysis and discussion of the findings. It began by outlining the underlying principles in community home-based, so as to illustrate the existing gaps in the CHBC model. The approach in CHBC model, which is based on the idea that communities are willing and capable to provide free services, seems to be flawed. This was shown in the profiles of women in which the needs of caregivers were highlighted. Having journeyed with the women participants in the study, I came

to recognize the fundamental role of their work. The opportunity provided a wonderful experience to listen to, understand, and validate the different voices, and begin to recognize collective experiences of these women as caregivers – “experiences that have been traditionally hidden, devalued, and unacknowledged” (Aronson, 1991 cited in Hooyman & Gonyea, 1995: 347).

This chapter has also shown that in order to sustain a CHBC programme there is a need to distinguish between the needs of PLWHAs, the needs of voluntary caregivers, and finally the needs of the CHBC training organization. Even though the findings have shown that the needs of caregivers are often overlooked, those needs are not very different from the needs of the PLWHA and their families. It emerged from the study that both PLWHAs and their caregivers have socio-economic, political, emotional and social needs. However, needs specific for PLWAHs would include a need to receive care, while a need for experience that leads to employment would be the major need for caregivers. As reflected above, the CHBC training organization works under financial constraints and their need would be access for more funding, in turn, provide quality service in the area of training. In conclusion, I contend that the CHBC as a health model, should not only seek to alleviate pressure placed on hospitals, but should include attempts to prevent the unnecessary cost placed on women caregivers. The public policy on social development should aim to transform the practice and provision of CHBC, with the leadership provided by the government. If not, women involved in caregiving should begin organizing for collective social action.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

In chapter 4, I have highlighted the key components of the CHBC training content, and also provided the context in which voluntary caregivers operate. While acknowledging the crucial role of CHBC, in chapter 5, I outlined the gaps between the CHBC training content and what actually happens on the ground. Having outlined how the CHBC training curriculum emphasizes practical aspect of care, while overlooking the context of caregiving, I was able to arrive at a conclusion that the CHBC training does not fully consider the needs of voluntary caregivers. The training seems to be concerned about practical skills, while the needs of voluntary caregivers include emotional, technical and financial needs. Now what? I now present the recommendations and conclusion from the study. Conducting this study has been enlightening and challenging at the same time. I had a unique opportunity to learn from the experiences of voluntary caregivers working in the area of CHBC, who work under extreme poverty but with a strong will and determination in their hearts to offer hope to PLWHA and their families.

As stated in previous chapters, the objective of the study was to examine the effectiveness of the CHBC training in preparing volunteers for the challenges experienced in individual homes, and also ascertain how the training helps them to confront their own fears and problems before dealing with those of others, how the training built on the wealth of experiences of caregivers, and finally explore how voluntary caregivers deal with their own life situations and face the challenges of their work as caregivers.

6.2 MAJOR FINDINGS AND RECOMMENDATIONS

The subsequent section summarizes the major findings, while incorporating the recommendations in the discussion.

Lack of support and care for voluntary caregivers

The findings presented the many benefits of a CHBC programme within communities, thus validating the crucial role and function of voluntary community caregivers. However, along with these findings, the study also argued for a need for genuine development to take place in the training of voluntary caregivers. The study revealed the need to provide participants in such trainings with an education programme that enables them to link their struggle with the multiplicity of demands at the level of communities, thus allowing people to make connections.

These observations demonstrate to service providers and other key role players in the field of CHBC that there is a need to design programmes that simultaneously respond to the needs of PLWHA, while responding to the needs and well-being of voluntary caregivers. This, in turn, should ensure a conducive and supportive environment for care, and probably decrease the levels of stress in women volunteers.

The needs of CHBC trainers

The study has shown that there is a need to consider the training provided to CHBC trainers. This, therefore, calls for good training to be offered for CHBC trainers in order to build their skills and confidence, so that in turn, they could provide quality training to voluntary caregivers.

Some of the problems related to the training as indicated in the study could be attributed to a lack of clear information on the part of who trains the trainers in CHBC. In this regard, the study has identified major discrepancies in the practice of CHBC, and this in turn has serious implications in the provision of CHBC training.

A need for a clear policy in CHBC

The findings indicated a need to reinforce the needs and rights of caregivers in the context of CHBC. The study further illustrated the symptoms of stress observed in

almost all voluntary caregivers, some of which is due to feelings of inadequacy as they feel that their needs are overlooked and rarely appreciated, thus resulting in stress and burnout.

Unfortunately, due to a lack of clear policy on CHBC, women voluntary caregivers are not protected from the abuse and exploitation often experienced in their field of work. The study demonstrated that in the CHBC training organization under investigation, voluntary caregivers are provided with an extremely short course in CHBC and thereafter they are expected to offer a free service in their local communities. However, due to socio-economic problems such as poverty and unemployment in South Africa, service providers need to begin investing systematically in their voluntary caregivers.

A need to put volunteers on a career path

It is hoped that a clear policy in CHBC will also enforce rules and regulations for CHBC service providers to offer only accredited courses, so as to put voluntary caregivers on a career path. A large percentage of voluntary caregivers interviewed indicated that they would leave voluntary work should opportunities of employment arise. Therefore, because of the lack of opportunities, caregivers often hope that volunteering will lead to remuneration that will enable them to improve their own and their families' lots. The service providers and policy makers should focus on the long-term impact of HIV and AIDS, and begin to recognize that in order to sustain the CHBC services, there needs to be quality care and support given to voluntary caregivers. Therefore, there is a need to develop a policy on CHBC that could provide standardized guidelines that could be used to assess the violation of and put in place protection for the rights and needs of voluntary caregivers. Even though some CHBC organizations provide certificates of attendance after completion of their training courses, these do not have the potential to put caregivers on a career path, as they are provided by organizations that are not accredited with SAQA. The CARE Project, an international NGO based in Johannesburg, needs to be commended in this regard. This organization has a policy on a career path for voluntary caregivers. The organization could be contacted for those interested in learning from the best practice model in the field of CHBC.

A need to review CHBC curriculum design

The findings in the study revealed that at present, the CHBC training does not incorporate skills in counseling, instead CHBC participants are referred to other organizations for further training. In many situations, those who have been trained in CHBC could continue offering care and support to PLWHA and their families having not obtained any skills in counseling. The study highlighted some of the key challenges associated with voluntary caregivers who possess no skills in counseling. However, the study findings identified the need and place of counseling in CHBC practice as part of a comprehensive package. Among other benefits of counseling, it is vital in showing the participants how to relate to grief-stricken homes and also how to deal with grief in their own lives, thus making voluntary caregivers aware of their own need for support and counseling. Therefore, a recommendation could be made to policy makers, curriculum developers, and other relevant stakeholders in the field of CHBC to revisit their CHBC curriculum and try to observe if it is relevant in addressing the many challenges experienced by voluntary caregivers. A recommendation could be to incorporate counseling into the training of CHBC.

A need for women empowerment in the context of CHBC

A recognition was made in the study that the CHBC programme is largely driven by women voluntary caregivers, some of whom are also infected and affected by HIV and AIDS. The study has been critical of governments who tend to shift the responsibility of care to communities and families, using unpaid women caregivers as a cost-saving exercise. In the context of CHBC, the study has attempted to illustrate the burden that women must carry in meeting the needs of PLWHA and their families, while their needs are left unmet. The CHBC training has not effectively offered an opportunity for women to deal with their own feelings and fears while dealing with those of others. Consequently, some women caregivers are afraid to disclose their HIV+ status to those closest to them, while others are too scared to go for HIV testing. In addition, the study revealed that a small percentage of women caregivers interviewed have no means and tools of moving out of abusive relationships since they are financially dependent on their partners.

Seeing that only women play a key role in CHBC, it is recommended, therefore, that women are included in community development planning. It is my belief that policy makers, together with other relevant stakeholders can benefit from the wealth of experiences that the women voluntary caregivers possess. The views, knowledge, and skills of the women should be fully accessed and constructively utilized for the benefit of everyone involved in community development.

A need to organize for a collective social action agenda

There is a need for civil society organizations to begin to find a common vision, channel their energies towards lobbying and advocating for the rights of caregivers and strive for a coordinated effort, so as to radically transform the lives of the women involved in voluntary services. In that way, the government should be reminded that they could no longer assume that members of communities are readily available to offer free services. Therefore, there is a need to challenge the long held values that poor people must always share because 'they are used to it'. The practice of community home-based care should not be based on a false assumption that poor people are 'happily poor', while the government spends money in the absence of war on defence and other arms ammunitions.

Civil society organizations in South Africa have a rich history in the fight for social justice. I am strongly convinced that, collectively, these organizations are capable of giving a voice to the many voiceless women in CHBC. The civil society organizations need to move voluntary caregivers from invisibility to visibility. To exercise this prophetic role within the context of volunteerism in CHBC, civil society organizations need to advocate for the needs of poor women by lobbying the government to review its policies on community care.

6.3 DISSEMINATION OF FINDINGS AND RECOMMENDATIONS

The two organizations that participated in the study have expressed their interest in learning from the findings of the study. The preliminary findings of the study were presented at a 3-day conference organized for faith-based organizations on HIV and

AIDS in October 2005⁵⁷. The presentation at the conference only focused on the context of caregiving, illustrating the reason why a greater involvement is needed from the government. It is also hoped that the findings would be further disseminated through local publications, conferences, workshops and journals.

6.4 A NEED FOR FURTHER RESEARCH

There is a greater need for other interested researchers to explore the research further. There is a need to explore the relevance and significance of volunteers within a South African context, also highlighting the characteristics and qualities of a volunteer in our context with the high rate of unemployment and poverty. It will also be of interest to explore a curriculum that integrates counseling and CHBC, and begin to pilot the course.

My major suggestion for further research would be to conduct a similar study, but making it a comparative one while using a larger sample size. Due to time-constraints, I was limited to working with a small size sample only, but I am certain that a larger sample could generate interesting findings. Therefore, instead of working with a group of only 10 voluntary caregivers from a single organization, further research could look at the lives of caregivers working in different organizations. This kind of research could also focus on the beneficiaries of care, that is, PLWHA and their families – so as to learn firsthand from their experiences.

6.5 CONCLUSION

Due to the design chosen for the study, I was afforded an opportunity to learn from the experiences of voluntary caregivers. The study revealed a need for the practice and provision of CHBC to incorporate the needs of caregivers as part of the package of comprehensive care to people living with AIDS, because the quality of care for PLWHA could only be assured if the needs and well-being of caregivers are taken into serious consideration.

⁵⁷ Conference took place on 19 – 21 October 2005 under the theme: Broken Bodies and Healing Communities, Faith-Based Contextual Responses to HIV and AIDS. The conference jointly organized by the University of KwaZulu-Natal (School of Theology and Religion), Diakonhjemmet, and University of Oslo in Norway

Given the current situation in South Africa and the enormous challenges facing communities as a result of the impact of HIV and AIDS, the challenge for society is to rethink the concept of voluntary caregivers and in so doing enable them to participate in transforming their own lives and that of their communities. The study has clearly shown that there needs to be a recognition that voluntary caregivers cannot afford to provide unpaid labour when they are impoverished themselves. Our society needs to acknowledge and reward the meaningful contribution that voluntary caregivers are making in their communities and focus on finding creative and effective ways of supporting them. As already outlined in the study, I believe that there are many ways of doing this, but one of the key roles that society could play is ensuring that voluntary caregivers are provided with quality CHBC training.

In conclusion, the study clearly indicated a mismatch between the CHBC training and the reality of work. The training tends to put more emphasis on practical aspects of care, thus overlooking the other aspects such as counseling and empowerment of voluntary caregivers that could enable them to provide optimal care. It is hoped that the findings will contribute to the enhancement and better provision of community home-based care.

“When I think of knowledge, skills, and strength, I usually remember the women” (Hurtado, 1996)

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INTERVIEW GUIDE FOR VOLUNTARY CAREGIVERS

Setting the scene

(Introductions, purpose of the research, request to write responses)

Questions about the caregivers' profiles

(Who they are, where they come from, and what they want from life)

Questions about the work of caregiver

- Describe your typical day as a caregiver – what are the kinds of chores you do/ responsibilities you take on?
(Probe for routine and scope of tasks)
- What gets you out of bed in the morning?
(Probe for motivation)
- What do you like doing most/ least?
(Probe for detail of chores)
- What is the hardest thing you had (have) to do?
(Probe for particular stories to illustrate how taxing the work is)
- What kind of skills and knowledge do you need in order to do the work?
(Probe for essential caregivers' skills and knowledge)
- What do you do in order to cope with the stress in your work? What kind of support, if any, do you get?
(Probe for individual strengths and networks, means of social, and emotional support)

Questions about the training content

- Looking back on the training, what was the most useful thing that you learnt on the course?
- What more would you have liked to learn?
- What did you learn about HIV and AIDS that you didn't know before?
- *Refer* to descriptions of daily routines – what did you learn that helped you to cope with X?

Questions about the training methodology

- Can you describe how the teaching went? What happened? What did you or other participants do?
- How was this teaching different or the same as other workshops you have attended?
- What did the facilitators do in order to help you to build on your experience?
- What do you think might have been done differently?

Finally, what advice would you give to someone who wants to become a voluntary caregiver?

HIV patients swell at King Edward



EPIDEMIC ... Outpatients and visitors leave King Edward VIII hospital in Durban. A leading HIV/AIDS expert this week said 90 percent of people attended to at the hospital are HIV-positive
Picture: Mandela Wkhize

By WONDER HLONGWA

NINETY percent of patients attended to at King Edward VIII hospital in Durban "are HIV-positive". And the rate could be as high in other hospitals.

This is the grim reality painted by leading HIV/AIDS expert, Professor Quarraisha Abdoel Karim of the University of Natal's Nelson Rolihlahla Mandela medical school. She is also the director of the Southern African Fogarty International AIDS training programme.

As an academic hospital King Edward is attached to the university's medical school.

"South Africa is entering a period that will be marked by rapidly rising death rates," said Karim at the South African AIDS conference in Durban this week.

In an interview with City Press she said the situation is exacerbated by the fact that people who were infected in the early 90s and mid-90s were the ones who were sick and dying now.

"If you were to go to the King Edward VIII adult medical ward and paediatric wards you will find that 90 percent of patients are there as a result of HIV/AIDS."

related illnesses," said Karim. "I always thought it was KwaZulu-Natal only where we had a problem of finding space to bury people. However, while speaking at the conference, people from other provinces told of the same thing in their provinces," said Karim.

The province's cities of Durban, Pietermaritzburg and Port Shestone are increasingly running short of burial space and Durban has resorted to the "recycling" of graves. This means a grave used over 10 years ago can be used again, provided the deceased in the second burial is related to the first.

KwaZulu-Natal has the highest HIV/AIDS infection rate. Hospitals such as McCord have come up with contingency plans to help infected people who can afford antiretroviral drugs.

McCord hospital's Sir Kithemba (Give Us Hope) clinic, which caters specifically for HIV/AIDS infections, has proved to be an immense success.

It was featured recently on the BBC website for its success in the distribution of anti-retroviral drugs and assisting those infected with the disease.

Minister praises KZN Aids-care volunteers

PATRICK LEEMAN

THE fight against HIV/Aids would be won not in the hospitals but in the community with home-based care, the Minister of Health for KZN, Dr Zweli Mkhize, said this week.

Speaking to 1 000 volunteers who support people with HIV/Aids in the

eThekweni municipality, the KZN health minister said that the issue of anti-retroviral drugs would be of no avail to people with HIV/Aids if there was no support at home.

He said the number of people with HIV/Aids was so high that the authorities would never be able to treat them all in hospitals.

More people were being treated outside hospitals than in hospitals, Mkhize said, and this support was thanks to the people who administered home-based care.

The minister said that 110 000 women had already been counselled in terms of the campaign to prevent the transmission of HIV/Aids from

mother to child. It was hoped that the provincial authorities would be in a position to administer Nevirapine to curtail the incidence of mother-to-child transmission at every clinic in the province by the end of the year.

Mkhize handed out nutritious products and dental hygiene packages to members of support groups.



MKHIZE