UNIVERSITY OF ZULULAND

THE IMPACT OF THANDUKUPHILA HIV/AIDS COMMUNITY BASED-CARE CENTRE IN ENSELENI-KWAZULU NATAL

By

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DEDICATION

I dedicate this dissertation to my dearest parents Fikile and Nhlanhla Mchunu who have been the pillar of strength and source of hope and inspiration from the cradle to the present. Also to my son Sthabiso for the patience and understanding you gave your mother throughout the time I was dedicated to this research. Lastly, to my distinguished fiancée Musawenkosi Mwandla for his tireless support and constant presence, both physically and in prayers so that this mission could become a reality. Without your love I would never have come thus far.

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I wish to express my sincere gratitude to:

TABLE OF ACRONYMS

The following acronyms and terms are used throughout the thesis. They are listed here for reference and clarity.

AIDS- Acquired Immune Deficiency Syndrome

HIV- Human Immune Virus

HIV/AIDS- Human Immune Virus/ Acquired Immune Deficiency Syndrome

PLWHA- A person infected with HIV or AIDS commonly referred to as Person Living with HIV/AIDS

CHBC - Community-Home Based Care

CBC -   Community Based Care

HBC -   Home Based Care

OVC- Orphans and Vulnerable Children

ABSTRACT

KwaZulu-Natal is at the heart of Aids pandemic, with HIV prevalence figures consistently higher than other provinces.The basic purpose of this research is to assess the impact of Thandukuphila HIV/AIDS Community Based - Care Centre on the lives of HIV/AIDS infected and affected people (beneficiaries), which is situated in a rural township established on the precincts of a vast tribal area in the northern part of Kwazulu-Natal province.

This HIV/AIDS Community Based - Centre was initiated as a response by some community members, initially it was church based, the church was challenged by the difficult health problems and social situations experienced by some of their community people, who were being devastated by the disease, HIV/AIDS, both inside the township and the neighboring rural area.

In–depth interviews were utilized to seek more information from these knowledgeable individuals regarding their own and other peoples' experiences, who are beneficiaries of Thandukuphila and, also those involved in many other ways.

A purposive sample of nine participants' from Thandukuphila CBO, which is situated at Enseleni was purposefully selected for the study. All participants were beneficiaries of Thandukuphila Community based care centre. These individuals were identified for their potential to elicit valuable information since they are beneficiaries of the programme. The individuals were also identified according to the criteria for inclusion. There were four groups of participants: i) PLWA, ii) OVC, iii) Caregivers/Volunteers, iv) Committee members.

The review of literature gives some detailed analytical views on the prevalence of the pandemic HIV/AIDs in Kwa-Zulu Natal. The aspect of community –home based care is discussed, for the role it is playing as well as the contribution it is making, albeit, in a limited manner because of resources, expertise and support from formal authority structures.

The narrative discussion intertwines quotations with the author's interpretations. Also in data analysis the researchers "seek to identify and describe patterns and themes from the perspective of the participants" Creswell (1994:167). Throughout the study report the research hints at limitations the organization has to contend with and these are briefly indicated in a nutshell towards the end.

The set objectives for the study were achieved. The findings indicated that Thandukuphila Community Based -Care Centre has a positive and significant impact on the lives of HIV/AIDS infected and affected people, who are beneficiaries of the program. However, it is the researcher's informed opinion that responsible Government Departments need to put more effort on assisting since they have professional personnel, in monitoring and evaluating the standard of services rendered by these Community Based Care Centres.

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CHAPTER ONE

1. ORIENTATION OF THE STUDY

1.1. INTRODUCTION AND BACKGROUND

Initially, HIV infections seemed mainly to be occurring amongst small group of homosexual men. The first recorded case of HIV/AIDS in South Africa was diagnosed in 1982. In 1985 it was clear that other sectors of society were also affected. Towards the end of the decade, as the abolition of Apartheid began, an increasing amount of attention was paid to the AIDS crisis. One of the major aspects focused on was the care of such affected and infected people as the formal treatment and caring facilities were stretched to the limit.

South Africa has the highest number of people infected globally, estimated at around 5.7 million, about 25% of the population, including 300 000 children under the age of 15 years, in 2007 (UNAIDS, 2008). The HIV/AIDS prevalence rate in South Africa is given as 18.8 percent compared to 6.1 percent in Sub–Sahara Africa and 1.0 percent globally. The report also indicated that an estimated 350,000 people had died in South Africa as a result of the disease that had assumed epidemic proportion. This shows that South Africa's HIV/AIDS prevalence rate is much higher than other Sub-Saharan African region and is among the highest in the world. It has been noted that the prevalence has reduced slightly however, South Africa still has the sixth highest prevalence of HIV in the world, with 18.1% of the population estimated to be infected (UNAIDS, 2008).

Dorrington, Johnson, Bradshaw and Daniel (2006) emphasize that new infections are still increasing. The national average of HIV-positive women attending ante-natal clinics in 2005 was 30.2%. The province of Kwa-Zulu Natal continues to have the highest prevalence at 39.1% followed by Mpumalanga at 34.8%. (NSP 2007-11). This shows that the province of KwaZulu-Natal is at the heart of Aids pandemic, with HIV prevalence figures consistently higher than other provinces.

Karim (1998:17) one researcher also asserts that, comparatively speaking, HIV/AIDS is more advanced in some provinces such as KwaZulu-Natal, Mpumalanga and Gauteng and refers to the fact KwaZulu-Natal as the province hardest hit by the HIV/AIDS, which has reached epidemic status. He further explained that anonymous population-based surveys conducted in KwaZulu-Natal have demonstrated that HIV/AIDS is about four times more common among young women between the ages 15 and 25 years compared to men. He also identified that the ante-natal survey conducted in Hlabisa, a rural district in KwaZulu-Natal, demonstrated a rapidly rising infection incidence among women between the ages of 15 and 30 years.

Like it happened before in South Africa that migrant workers who had been in the cities' industrial areas and the mines returned "home" to the rural, mainly tribal areas, when they became sick and disabled, the same has been observed in respect of the HIV/AIDS infected and affected people. Hence for many years now, the burden of care and support of infected and affected people has fallen heavily on the shoulders of impoverished rural communities where sick family members return when they can no longer work or care for themselves near areas of work.

 Russell & Schneider (2000) clearly posed the view that 'community-based care had been promoted as the best option, in supplementary and alternative care, since it would be impossible to care properly for hundreds of thousands of people affected by HIV and dying of AIDS in public facilities. In the decade of the 90s concerted attention has been paid in terms of policy, in charting the way forward in dealing with the epidemic such as the "The National HIV/AIDS/STD Strategic Plan for South Africa (2000-2005)".

Community -based care, as a concept has become central, in policy and implementation, as a form of alternative treatment, care and provision in dealing with the epidemic of HIV/AIDS. As it progressed, the need for community- based services and resources also become critical, as the hospitals and present structures are stretched beyond their capacities and could not cope with the increasing demands of looking after HIV/AIDS infected and affected people. Russell & Schneider, (2000) share the view of many other writers on the subject that realistically community based care programs are far better than having an infected and affected person attended to by a family, who may not always have

necessary skills or means to advice or look after, while at the same time have to deal with the psychological and emotional aspects involved.

Ncama (2005) also emphasizes that the HIV/AIDS epidemic has placed a large burden on public health facilities in developing countries that are already functioning with limited resources. This has shifted the burden of care to families and communities, because public health services are often stretched beyond their capacities. A number of community/home-based care and services have evolved in response to this need.

As more and more people were infected and affected by HIV/Aids, the Enseleni community, like many other communities in South Africa, felt a need of responding to the worsening situation by starting a program to help deal with the situation. Thandukuphila Community Based -Care Centre came into being. (Thandukuphila is a compound comprised of two words: Thanda and Ukuphila; Love your Life.) It is a community-based organization for HIV/AIDS infected and affected people of Enseleni and surroundings. Thandukuphila Community Based -Care Centre is a community-based initiative situated at Enseleni Township, a semi-rural community in the North Coast Region, of KwaZulu-Natal. It is under KZ292 categorization .It is situated just outside the town of Richards bay, which is an industrial and terminal zone.

This centre was established in 1996 by a group of concerned Catholic women who were trained by Ngwelezane Hospital, a regional hospital, as care givers. They had seen their friends, as well as other faith members, their neighbors living with HIV/Aids under difficult conditions and also dying without any visible support neither government nor community. During their home visit, as community volunteers, they discovered that in some families, the breadwinner would be the one terminally ill from the HIV/AIDS and consequently the family was starving. Children were orphaned and some were forced into a difficult role of assuming the head role in their families, as both parents were deceased.

This facility started off as a crèche for children from infected and affected families. Later the facility developed into what it is today, a Community Based- Care Centre. In 2000, the Departments of Health and the Welfare (then, now Social Development) offered their support and also formally developed Thandukuphila Community Based -Care Centre. The Centre currently operates outreach program that include an extensive home based

care program, feeding scheme for school going children, orphans and vulnerable children, (OVC) income generating projects for (People Living with HIV/AIDS (PLWA), OVC and Caregivers), Day care for all underage OVC, support group program for PLWAs, caregivers' horticulture project, counseling services, educational program, luncheon club and school fees fund.

1.2. STATEMENT OF THE PROBLEM

HIV/AIDS is spreading at a rapid rate throughout South Africa. There are many factors that contribute to the spread of HIV/AIDS in South Africa, especially KwaZulu Natal. These factors include, but not limited to: poverty; low levels of education impacting on knowledge acquisition; social instability; the low status of women making them unable to negotiate assertively in relationships; sexual violence; high labour mobility (particularly migrant labor); limited and uneven access to quality medical care and health education.

Enseleni area is part of poor semi-rural area of North coast region, which is overwhelmed by the HIV/AIDS pandemic. Statistics revealed that the prevalence of HIV cases among pregnant women is still high in this community. Many researchers agree that there have been some indigenous responses to the needs of those infected and affected by HIV/AIDS, which include provision of care for terminally ill adults and care for children from affected families. Many non-governmental organizations in South Africa have concentrated mainly on helping their communities to care for the infected people and orphans.

Thandukuphila community -based program is an indigenous community care program, whose aim is to facilitate the development of sustainable community-based care for infected and affected people (orphans & vulnerable children, positive living people). The statistics reflect that more needs to be done to meet the challenges of caring for children orphaned by HIV/AIDS and people living with HIV/AIDS in any community in this country.

Therefore, this study was being undertaken to establish the extent of the impact Thandukuphila Community -Based Program has on the lives of HIV/AIDS infected and affected people of Enseleni and the effectiveness of these programs in addressing HIV/AIDS issues in the community. The investigation also looked at the Inter-sectoral

Collaboration Strategy as one of the vehicles in the struggle to minimize the spread of HIV/AIDS. No one organization or effort can even succeed to make a meaningful dent on the pandemic singly.

1.3. MOTIVATION OF THE STUDY

The researcher is a social worker who has worked at Thandukuphila Community- Based Care Centre; she became interested in conducting the study so as to establish and explore the impact the project, moreover to see if it makes any meaningful contribution to address the needs of beneficiaries of this project. The intensity of the problem of HIV/AIDS has been reflected in the striking increase in research work and writings on the topic. Most of the written work dealing with HIV/AIDS has documented that one of the major issues that face individuals with HIV/AIDS, infected or affected, is the lack community -based care support programs especially in the rural areas where usually the health and welfare infrastructure has been very inadequate.

In South Africa there is a serious paucity of empirical data on community- based care program for infected and affected people. The few studies conducted in this country and elsewhere on Community- Based Care program only tagged on questions related to policy planning and implementation. There remains a need for studies that would explore the impact of these programs or community -based facilities on the beneficiaries, caregivers and affected community members and families. The Centre for AIDS Development, the research and Evaluation (CADRE, 2004) contend that there has been little systematic studies of community responses to HIV/AIDS. Much of what is known is descriptive and comes from reports by non-profit organizations, development agencies and project managers working at community level. In many cases, these reports focus on particular types of response, such as programs for orphans and vulnerable children or home based care programs.

To the knowledge of the researcher little, if any, research has been undertaken on quantifying community -based responses as a whole and on exploring how such program initiatives interface with other types of activities within a given community. In addition, there has been, rightly of course, a great deal of pre-occupation with creating awareness i.e. conducting educational campaigns and attempts at preventing the spread of the virus,

while the provision of care and the evaluation of existing community based strategies remain largely ignored (Russell &Schneider, 2000). This has, therefore, raised the researcher's interest as to what impact does this centre has in addressing problems of HIV/AIDS infected and affected people at Enseleni and the surrounding areas.

1.4. OBJECTIVES OF THE STUDY

The main objective of this study was to assess the impact of Thandukuphila Community-Based Care Centre, on the lives of HIV/AIDS infected and affected people living in the Enseleni Township and surrounding areas.

More specifically, the study also aimed to:

1. To assess the appropriateness of the program/ service provided in meeting the needs of beneficiaries.

2. To explore the experiences of beneficiaries of the program in addressing HIV/AIDS issues in the community.

3. To ascertain the level of accessibility and participation of HIV/AIDS infected and affected community.

1.5. SIGNIFICANCE OF THE STUDY

Thandukuphila Community -Based Care Centre is a practical demonstration by the community in response to a concern of a health and community welfare nature that need urgent attention, i.e. how to provide a caring service for people who are infected and affected at community level by drawing and mobilizing appropriate resources through this organization and facility.

To the researcher it definitely appears that very little has been done to assess the impact of these Community- Based Care Programs, and as already stated, how best they fit in the overall strategy in fighting the pandemic. This study intended to fill the gap identified in our knowledge of Community -Based Care Centres and the impact these would have in the lives of infected and affected people.

1.6.   DISSEMINATION OF FINDINGS

The researcher is of the view that all the stakeholders involved in this research project such as Enseleni community, Thandukuphila Centre itself, the Departments of Social Development, Health, and NGOs as well other similar programs elsewhere in South Africa would find the results of the study particularly valuable since it would provide an added dimension in dealing with issues that needed to be considered in delivering services to such infected and affected people, making use of such facilities and programs they are capable of adding.

1.7.   RESEARCH METHODOLOGY

The method that was used to implement the research process involves the following research stages:1) the design of the research, (2) sampling and research tool, (3) the collection of data, and (4) the analysis of data.

1.7.1   RESEARCH DESIGN

A scientific work adequately planned, with a well-defined methodology, assists the researcher to obtain the intended and convincing results. Babbie and Mouton (2004) define the process of research design as the plan and structured framework of how you intend conducting the research process in order to solve the research problem and or find answers to the issues being studied. In addition they state that research methodology refers to the methods, techniques, and procedures that are employed in the process of implementing the research design.

For the purpose of this study an explorative-descriptive methodology was used.

1.7.1.1   EXPLORATORY DESIGN

Exploratory research was conducted to gain insight into a situation, phenomenon, community or individual. It aims at gaining familiarity with a phenomenon or achieving new insights into it, in order to formulate a more precise problem or to develop hypotheses. Generally exploratory research has a basic research goal and researchers frequently use qualitative data to obtain an inside perspective on social action (Babbie and Mouton, 2004).

Babbie (2004:9) outlines three purposes of the exploratory study:

1. To satisfy the researcher's curiosity and desire for better understanding of the problem;

2. To test the feasibility of the study being undertaken; and

3. To develop methods to be employed in a more careful manner

1.7.1.2   DESCRIPTIVE DESIGN

According to Sarontakos (2005) descriptive research design is quite common, in most cases as a preliminary study. It aims to describe social systems, relations or events, providing background information about the issues in question as well as stimulating explanations. Descriptive research presents a picture of the specific details of a situation, social setting or relationship, and focuses on how and why questions.

1.8   QUALITATIVE RESEARCH METHODS

The study adopted a qualitative research approach because it studies events in their own natural setting (McMillan &Schumacher,1993), (Creswell,1994). Strauss & Corbin (1990: 17) further indicate that qualitative research refers to the research about the people's lives beliefs, and behavior. Fraekel & Wallen (1990:37) add that qualitative research is concerned about the quality of particular activity than how often it occurs.

A qualitative research approach that is explorative and descriptive was used in this study. Qualitative research enables the researcher to study human action and interaction from the perspective of participants themselves (Babbie & Mouton, 2004). Thus, qualitative research method was appropriate for this study since the aim is to determine the impact, the value and indeed the benefit, of Thandukuphila Community -Based Care Programs, on the people, that live in the community of Enseleni and surrounding adjacent areas who are infected and affected by HIV/AIDS. It further explored the experiences and perceptions of beneficiaries of the programme in order to understand the dynamics of the circumstances involved from the participant's point of view as they live, interact and battle with issues affecting their survival.

1.9 SAMPLING

Silva, Menezes, Pezzi, & Lappoli (2001) define a sample as part of the population or the universe selected according to a rule or plan. A non-probability sampling technique was applied. A purposeful sampling was employed to recruit the participants. Purposeful sampling involves identifying individuals who are "appropriate" and from whom the researcher would be able to generate rich descriptions of the phenomenon. Social work research is often conducted in situations in which it is not feasible to select the kinds of probability samples used in large-scale social surveys, which often make probability sampling impossible or inappropriate, while non-probability sampling techniques are often more appropriate (Rubin & Babbie, 2001:253).

After careful interaction with some role players it became feasible to select a purposive sample of nine participants from Thandukuphila CBO which is situated at Enseleni were purposefully selected for the study. All participants were beneficiaries of Thandukuphila Community -based care centre. According to Patton (1997) qualitative research makes use of a small number of cases to study a phenomenon in depth. All participants were black Africans and Zulu-speaking, infected and affected by HIV/AIDS and living in Enseleni and surroundings. These individuals were identified for their potential to elicit valuable information since they are beneficiaries of the program. The individuals were also identified according to the criteria for inclusion. There were four groups of participants (i) PLWA, ii) OVC, iii) Caregivers/Volunteers, iv) Committee members).

1.10 DATA COLLECTION METHOD AND INSTRUMENT

Polit, Beck & Hungler (2004:53) define the instrument as the means of collecting precise information relevant to the objectives of the study. The collection of data is related to the problem, hypothesis or suppositions of the research and aims to obtain elements so that the objectives proposed in the research may be achieved (Silva, et al 2001).

In this study data was collected by structured, in-depth, face-to-face interviews. Interviews initially lasted from one to two hours. The in-depth interviews involve one-on-one, face-to-face interaction between an interviewer and the interviewee. In–depth interviews were utilized to seek more information from these knowledgeable individuals

regarding their own and other peoples' experiences who are beneficiaries of Thandukuphila and, also those involved in many other ways.

1.11 DATA ANALYSIS

Data analysis for this study was qualitative. The researcher took all the collected data and coded data and conduct content analysis by looking for specific words for which themes could be identified.

1.12 ETHICAL CONSIDERATIONS

The study adhered to all ethical specifications. Permission to conduct research was obtained from the participants. The researcher met each participant personally and spoke with him or her about the research, informing him or her of the purpose of the study. A letter was presented explaining the aims of the study and what would be expected from participants. IsiZulu was the first language of all participants; therefore, a translator was not needed as the researcher is a Zulu a speaking person. The letter was distributed to all participants and was read through with participants who were capable of reading.

Participants were given time to ask questions. The letter informed participants of the amount of participation and time required. Participants entailed, answering an interview questions, and signing a consent form agreeing to participate in the study. Participants were informed that each session would be between 30 and 60 minutes, would be audio-taped and then transcribed. Participants were made aware that findings would be presented in the form of a paper handed in for examination. Confidentiality and anonymity was guaranteed. Participants were informed that they would be given a code name to ensure their privacy.

The study posed no risk to participants physically. Due to the sensitive nature and complexities of people who are beneficiaries of HIV/AIDS programs and emotions that may have been evoked during the interview, counseling services was made available since researcher is a social worker, this have been warranted. None of the participants requested or required counseling or debriefing following the interviews except support and guidance.

Ethical clearance was obtained from the Thandukuphila Community- Based Care Centre, the Ethical Review Committee and the Research Committee of the University of Zululand. It was important to ensure during the recruitment process that participants understand what their participation in the study would involve. Information about the research, as well as the consent forms were written and explained in Zulu, and written consent forms were obtained from each participant. They participated voluntarily, and were informed that they could withdraw from the study at anytime should they so wish. The ethical concern of the research was extended beyond confidentiality to a desire to provide a supportive environment for participants

1.13 EXPOSITION OF CONCEPTS

The exposition of concepts is aimed at helping the reader to understand the contextual use of certain words in this study. The focus will be on the following concepts: HIV/AIDS, Community –home based care.

1.13.1 HIV

HIV is the virus that causes AIDS. The term HIV is the acronym for Human Immunodeficiency Virus:

- Human, because it attacks and destroys the blood's immune system.

- Virus, because it shares biological characteristics with other viruses that are not common to living cells.

It kills an important kind of blood cell -- the CD4 T lymphocyte, or T cell. These T cells are the quarterbacks of the immune system. As they die off, the body becomes more and more vulnerable to other diseases. The diseases they cause are called opportunistic infections .When people with HIV get these infections or when their CD4 T-cell levels get too low ,they have AIDS.

1.13.2 AIDS

AIDS is the acronym for Acquired Immune deficiency Syndrome.

- Acquired means that disease is acquired in the sense that the infection is not inherited, it is caused by virus which enters the body from outside. Immunity

refers to the body's natural defense system which protects it against infection and diseases.

- Deficiency indicates the defense system is inadequate

- Syndrome is a group of specific signs and symptoms that occur together and are characterized of a particular pathological condition.

It is a collection of symptoms and infections which results from the specific damage to the immune system due to the human immunodeficiency virus (HIV) in humans.

1.13.3 COMMUNITY-HOME BASED CARE

Community-Home Based Care is care that is provided to a patient or client within his or her own community. It seeks to promote community participation and networking between all organizations within the community. Community- based care includes medication management (including infusions) infusions palliative care and social support.

Home based care is an aspect of community based care that focuses primarily on physical /medical and palliative care of the patient at home, with the support of family and the immediate community (Russell &Schneider 2000). For the purpose of this study, community-home based care is referred to the care and support given to HIV/AIDS infected and affected beneficiaries of Thandukuphila with the help of different community stakeholders.

1.14 LIMITATIONS TO THE STUDY

The study was undertaken in one rural area in the province of KwaZulu-Natal in a centre in existence for twelve years. It is not a big centre and its resources are limited. In such areas there are people, who because of their cultural beliefs, would not necessarily identify with such a centre, preferring to use traditional healers and other spiritual mediums. These are isolated people from the main stream community services since they choose or are forced by significant beings in their lives to behave like that. A comparison with similar projects elsewhere where they exist would create a bigger and better picture.

Methodologically, limitations relate to procedures and interpretations. Sampling procedure was limited to the population in one area. No other information, even from

relevant government departments, was available about the Centre to supplement the researcher's own procedures. The sensitivity of the investigation of this nature requires more time of real in-depth involvement with the stakeholders concerned. Resources of an individual investigation cannot afford the high cost factor that might be involved.

1.15 ORGANISATION AND STRUCTURE OF THE STUDY

Chapter 1: Introduction to the research project

The chapter focuses on the general orientation towards research report. It gives the motivation of the study for the study through the problem statement, aims and objectives and significant of the study. It further gives and indication of the research design, methodology and process that guided the research.

Chapter 2: Literature Review

It gives a theoretical perspective, from a literature point of view, on the background and the extent of HIV/AIDS Home Community -Based Care programs in Sub-Saharan countries including South Africa. The focus is on the impact and value of these programs on the lives of infected and affected community as well as the Government response towards HIV/AIDS programs.

Chapter 3: Community Profile of Thandukuphila

The chapter looked at the historical development of the Centre, services rendered as well as challenges experienced by it.

Chapter 4: Research design, Research Methodology and Data collection.

The chapter describes the research design and method that was used to conduct the research and for data collection includes details of the characteristics of the respondents, to a large extent from their perspectives and issues considered to protect the ethical rights of the respondents.

Chapter 5: Data Presentation and Data Analysis

The main focus of the chapter is on the presentation of the research findings, interpretation and analysis of the study.

Chapter 6: Findings, Conclusions and Recommendations

This is the last chapter; it concludes the study and presents recommendations that emerge for future research and interventions.

1.16 SUMMARY

The chapter has looked at the impact of Thandukuphila Community- based Care Project on the lives of people who are the service users of this project. South Africa, in KwaZulu-Natal which has the highest rate of infection with resultant affected individuals including orphans and vulnerable children. The project is, therefore, attending to the needs of People Living with HIV/Aids as well as Orphans and Vulnerable Children (OVC).

CHAPTER TWO

2. LITERATURE REVIEW

2.1. INTRODUCTION

The scourge of HIV/AIDS is recorded as one of the most destructive plagues in modern history. It is a monster that threatens to destroy the society because it is changing the rules by which we live. But we cannot despair just because we feel defenseless against it –we have to take decisive and practical steps to defend ourselves against it. What is necessary, and often lacking, is the willpower and commitment to do so. And there is no room for complacency: the statistics are frightening, and time is running out (van Dyk, A, 2005).

During 2007 more than two and a half million adults and children became infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS. By the end of the year, an estimated 33 million people worldwide were living with HIV/AIDS. The year also saw two million deaths from AIDS, despite recent improvements in access to antiretroviral treatment (UNAIDS, 2007).

Whiteside & Sunter (2000) state that the tragedy of HIV/AIDS is that it is a preventable disease and there was never any (inevitable) that it would become a devastative pandemic. As early as 1985, countries in Southern Africa were aware of the dangers related to AIDS. However, complex social, cultural and structural conditions such as migrant labor system that encourages separation of household members, with men working far away from their family places for extended period of times combines with high human mobility of people and a lack of political will, fuelled the spread of HIV/AIDS(Webb 1997: 35).

For many years, the burden of care and support has fallen heavily on the shoulders of impoverished rural communities where sick family members returned home when they could no longer work or care for themselves at or near their places of work. Community-based care has been promoted as the best alternative option since it would be impossible to care properly for hundreds of thousands of people dying from AIDS in public hospitals. (Dorrington, et al, 2006).

In the face of increasing needs of PLWHA and their families, and the inability of the formal health and welfare systems to meet these needs –particularly in sub-Saharan Africa, many countries have turned to Community Based Care and Support. Notable programs in Africa have been the AIDS Support Organizations (TASO) in Uganda, the Family AIDS Caring Trust (FACT) in Zimbabwe and the Catholic Diocese in Ndola in Zambia (Johnson's et al, 2001).

Williams, & Campbell, (1998) as quoted by Russell &Schneider, (2000) found that South Africa has one of the most rapidly growing HIV epidemic in the world. In South Africa a number of organizations have emerged to Community –Home Based Care (CHBC) as a community response as was noted that government response has failed due to increasing number of infected and affected people.

The impacts on health services, families and communities are emerging at a rapid pace. In an attempt to deal with impact, it is now common practice for health care facilities to ration services to the community. Much of the burden of HIV care in developing countries is now falling into households and communities (Russell & Schneider 2000).

Owing to the increasing number people developing HIV/AIDS there was a need for partnerships among family members, health care workers, local communities, and non-governmental organizations (NGOs) in providing care and support to those infected and affected by HIV/AIDS epidemic. Community home-based care centres were developed as the best option for caring for people with HIV/AIDS including HIV/AIDS orphans.

2.2. HIV/AIDS IN A SOUTH AFRICAN CONTEXT

HIV and AIDS have a severe impact in South Africa and in order to gain a better insight into the situation it is important to look back on the history of AIDS in South Africa. Different researchers and authors outlined the background of HIV/AIDS in South Africa (Aids Foundation of South Africa (AFSA), Dorrington, et al (2006) and UNAIDS, (2008).

Prior 1981, a virus evolved into what later known as Human Immunodeficiency Virus (HIV), many years before the first case of infection is officially recorded. Decades later, scientists speculated that HIV originated early in the 20th century, when simian

immunodeficiency virus (SIV), which causes an immune disease similar to HIV in apes, crossed the species barrier to humans, perhaps as results of bush meat hunting in Africa. Luc Montagnier (Pasteur Institute) and Robert Gallo (National Cancer Institute) identify the virus that causes AIDS-later named Human Immunodefiency Virus (HIV).

South Africa's first national ante-natal survey to test for HIV that first conducted in 1990 and found that 0.8% of pregnant women were HIV-positive. Yet, in the same year, ANC leader, Chris Hani, speaking from exile, warned: "Existing statistics indicate that we are still at the beginning of the AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century." This warning was not heeded, either by the outgoing regime or by the incoming democratic government as it faced the huge challenge of taking over political control of a divided country. Several AIDS information, training and counseling centres were established in 1991 and Red Ribbon was introduced as a symbol of AIDS awareness.

The government's first significant response to AIDS came when Nelson Mandela addressed the newly formed National AIDS Convention of South Africa (NACOSA) in 1992. The purpose of NACOSA was to begin developing a national strategy to cope with AIDS. The free National AIDS Helpline was founded. The Minister for Health accepted the basis of the NACOSA strategy as the foundation of the government's AIDS plan in 1994. There was criticism that the plan was poorly thought-out and disorganized. The South African organization Soul City was formed, with the aim of developing media productions to educate people about health issues, including HIV/AIDS.

In 1995 the International Conference for People Living with HIV and AIDS was held in South Africa. The first time that the annual conference has been held in Africa. The HIV prevalence rate among pregnant women was 17.0%. A national review of South Africa's AIDS response to the epidemic found that there was a lack of political leadership. The pressure group Treatment Action Campaign (TAC) was founded in 1998, to campaign for the rights of people living with HIV, and to demand access to treatment for all those who were in need of it. The Department of Health outlined a five-year plan to combat AIDS, HIV and STI's in 2000. National AIDS Council was set up to oversee these developments. At the International AIDS Conference in Durban, the former South

African President made a speech that avoided reference to HIV and instead focused on the problem of poverty.

Confusion also reigned in South African communities as highlighted by the beating to death of a sufferer, named Gugu Dlamini, by her neighbours in a township outside the city of Durban in KwaZulu-Natal after she had revealed her HIV positive status in a television program. The neighbors tragically thought she had a plague that would infect them. This was a tragic moment, people acting on the basis of lack of scientific knowledge, further aggravated by unnecessary public bickering instead of addressing the critical issues about the condition.

South Africa's High Court ordered the government to make the drug Nevirapine available to pregnant women to help prevent mother to child transmission of HIV in 2002. Despite international drug companies offering free or cheap antiretroviral drugs, the Health Ministry, remained hesitant about providing treatment for people living with HIV Later in 2003, the government finally approved a plan to make antiretroviral treatment publicly available. After that Nelson Mandela lent his prison numbers to 46664 AIDS fundraising campaign. These were government strategies to deal with this pandemic. In 2007, South African government revamped National Aids Plan, which aims to cut new HIV infections by 50% and provide treatment to at least 80% of HIV-positive people by 2011.This plan meets with wide national and international approval (Dorrington, et al, 2006).

2.3.   THE PREVALENCE OF HIV & AIDS IN KWA ZULU NATAL

Different authors contend that the number of the people infected with HIV/AIDS differs from province to province, but KwaZulu-Natal has the highest number of infections. They believe that some of the factors contributing to this are that it has no infrastructure as a result there is a large migrant labor population, is one of the poorest province, and the main transport route along the N3 route.

Karim (1998:17) agrees with the view that HIV epidemic is more advanced in some provinces such as KwaZulu-Natal, Mpumalanga and Gauteng. Kwazulu-Natal is the province hardest hit by the HIV/AIDS epidemic. He further explained that anonymous population based surveyed conducted in Kwazulu-Natal have demonstrated that HIV/AIDS is about four times more common among young women between the ages 15

and 25 years compared to men. He also identified that the antenatal survey conducted in Hlabisa, a rural district in Kwazulu-Natal, demonstrated a rapidly rising incidence among women between the ages of 15 and 30.Thandukuphila Community -Based Program is based in Enseleni, which is few kilometres away from Hlabisa.

2.4. HIV PREVALENCE AND POVERTY (A VICIOUS CYCLE)

There is no gainsaying the fact that there is a strong correlation between HIV prevalence and poverty. While the issue of poverty has not been debated at great length, particularly within South African context, because of political connotation in the past, this did not mean it did not exist. Ironically, it was seen as lack of development. However, it manifested itself in certain ways and became located within certain communities.

Poverty is not just the absence of material necessities. Poverty results in loss of self-respect, deep anxiety and loss of hope. It is hard for people who do not know how or whether they would survive until following week or month to choose to abstain or to protect themselves. One teenager in a rural community of Mpophomeni Township, in Kwazulu-Natal, was quoted by Lindiwe Buthelezi, a community health worker, in 2002 as having said "why should you spoil the little pleasure I have now with promises of saving myself for the future?" Poverty as a consequence of HIV infection could see the poor adopting various mitigation strategies to cope with disease that usually expose them to HIV infection. The impact of the HIV/AIDS epidemic is proving to be most catastrophic at household level. Increasing levels of HIV/AIDS morbidity and mortality pose a serious threat to food security and nutrition in households.

Families lose income earners, household expenditure is redirected to cover non-food items such as medical costs and funerals, children are taken out of school for lack of fees or to care for sick relatives, workers have to take time off to provide terminal care, resources may have to be shared with more dependents, and productive assets are sold off. The lack of an adequate social security network and high levels of unemployment in South Africa mean that poor households and communities slip further and further into poverty and deprivation. Invariably, the burden of coping falls on women, particularly girls and grandmothers (Dorrington, et al 2006).

HIV related ailment can result in a loss of employment and as a breadwinner, this would, therefore, greatly affect the person who is a breadwinner; consequently affecting household wealth. People with the status of full blown AIDS also suffer immensely as their economic status also suffer due to poverty. Employment and subsequent income loss, rejection, discrimination, stigmatization and finally ill health with subsequent death contribute to individuals and families misfortune and to overall cycle of poverty (Evian, 1993).

This shows that poverty contributes to HIV/AIDS and can be a cause of poverty because it affects a person's ability to work, often causing them to lose their employment. Several studies show that it is those who are poor who are most often infected by HIV/AIDS. It is indisputable that HIV/AIDS and poverty are associated. Poverty, per se instead poverty increase susceptibility to HIV infection and HIV/AIDS deepens poverty.

Aids Foundation South Africa (AFSA) (2000) contends that HIV/AIDS associated with poverty and social marginalization establishes a cause and effect relationship with the outcomes of the disease becoming contributing to its further spread. Unless national, governments, international bodies, NGOs, CBOs and faith based organizations step up their efforts, the vicious cycle of poverty, hunger and HIV/AIDS will intensify. Cohen (1998) argues that HIV intensifies poverty leads to its persistence and overtime generates a culture of poverty. When parents are sick and die from AIDS related complications, little or no transfer of skills and knowledge to the younger generations. The cycle of poverty is likely to repeat itself and felt over generations.

2.5. GROUPS THAT ARE MOST VULNERABLE TO HIV/AIDS

2.5.1 WOMEN

Women are extremely vulnerable to the effect of the epidemic. Women are responsible for caring for the sick and dying, while grandmothers and female siblings in particular have the added responsibility of parenting orphans and vulnerable children. Infants born to HIV positive mothers still face a significant risk of infection and children often have to care for their sick and dying parents before being left orphaned with little or no support (UNAIDS 2006). The women who are most vulnerable of all are those who are young and poor. Of the 33 million people living with HIV&AIDS globally, 50% are women,

however in Sub-Saharan Africa 59% of them are women.UNAIDS(2008) Report outlined that for the region (Sub-Saharan Africa) as a whole, women are disproportionately affected in comparison with men, with especially stark differences between the sexes in HIV prevalence among young people (15-24).

In a study conducted in Nyanza Province in Kenya by Becky et al, (2004) found that cultural and socio-economic factors are the main causes of high prevalence of this virus among woman. Traditionally, the male is a sole breadwinner in the family and deepening on his economic status may have two or more wives. Upon the death of the husband, his wife is inherited by his brother or other close relatives in order for the woman to be guaranteed continued financial support for herself and for her children. Before the ritual of wife inheritance is incomplete, each wife must undergo a cleansing ritual in which she is required to have sex with a stranger. If either the widow or the wife is infected with HIV/AIDS, his or her sexual partner may become infected with the virus, and the disease is then spread throughout the woman's new compound or to the wife cleansers other sexual partner. This shows that women are most vulnerable to HIV/Aids.

2.5.2 ORPHANS AND VULNERABLE CHILDREN

According to Dorrington, et al (2006) obtaining accurate statistics on the number of children orphaned as a result of AIDS is problematic. If orphans are defined as children from birth up to the age of 17 whose mothers have died, UNAIDS estimates that there were 1 400 000 children orphaned due to HIV/AIDS living in South Africa at the end of 2007. More than 10% of children in South Africa are orphaned. Where the cause is AIDS, there is a greater likelihood of vulnerability, due to the probability of the child concerned being infected with HIV/AIDS.

South Africa is currently experiencing an overwhelming HIV/AIDS pandemic. Many children are affected by HIV/AIDS as their parents, caregivers, families and members of their communities are infected with HIV or have become ill and die due to AIDS. Orphaned children are far better if they remain in familiar surroundings, in family units even if not with their biological families. At the same time, the pressures upon households, absorbing orphaned children can be overwhelming (Dorrington, et al, 2006).

South Africa is seeing increasing numbers of children in distress. A situation made worse by the collapse of traditional modes of care such as extended family. Rising unemployment levels mean that fewer and fewer adults are in a position to provide for the household. Adults in a prime of their working lives are also most vulnerable to HIV infection. The majority of orphaned children, regardless of their HIV status, live in deeply impoverished households. Apart from the loss of their parents, they face inadequate nutrition and poor access to education and health care. The deterioration in the well being of such children starts long before a parent dies. But by the time a child is orphaned, the extended family networks that have traditionally supported vulnerable members have been overstretched by the ravages of HIV and AIDS.

A case study of foster- care pilot project in Bushbuck ridge in Limpopo province suggested that there is a need to identify workable models to ensure that children are properly integrated into the community. This is one of the reasons Nseleni community started drop-in centre for orphans and vulnerable children. In situation where the deceased is a single parent, many orphans suffer a double loss because they are often unable to remain in the care of family member. These orphans require emotional and psychological support that is not available in poor communities. Mental health services are unavailable. However, innovative ways of helping children to deal with trauma have been developed and piloted. One project documented the use of memory boxes as a way of building up resilience in orphans and traumatized children in KwaZulu-Natal.

The HIV/AIDS pandemic compromises the basic rights of those children infected and affected by HIV/AIDS. Strebel (2004) clearly states that the importance of a human rights structure for OVC work needs to be emphasized. However, the illness of or death of a parent could limit a child's access to a nutrition and safe home environment, health, education, welfare services, this impacting negatively on the Childs ability to thrive and succeed through life (UNAIDS, 2006).

UNICEF (2004) emphasize that children and young people are more vulnerable than adults to being hurt, neglected, abused and exploited. Orphaned children in impoverished households are vulnerable to becoming involved in exploitative work, including the worst forms of child labor (trafficking, commercial sexual exploitation, being used by adults to

commit crime or to do hazardous work). They are also vulnerable to neglect and abuse, if they are not cared for by an adult who is willing and able to protect their interests. They may be pressurized to engage in transactional sex in order to meet their material needs, putting them at risk of HIV infection.

Another important issue is keeping children especially OVC in school. This has become one of the greatest challenges of the AIDS pandemic. The desire for education is great but the desire for survival is stronger. If school attendance is perceived as an obstacle to physical survival children will drop out of school or not enroll, thereby continuing the downward spiral and vulnerability of these children's lives.

The South African government has extended measures to support orphaned and vulnerable children, and the family networks and communities caring for them. For example, in 2009 it extended the Child Support Grant to all eligible children up to the age of 15 years and has committed to extending this up to 18 years. The Department of Social Development (DOSD) reported at the end of 2008 that 8.3 million children were receiving this grant, with almost half a million more children receiving a Foster Care Grant (FCG).

2.5.3 CHILD-HEADED HOUSEHOLDS

The phenomenon of child-headed households has attracted a lot of attention. Older children have shown tremendous resourcefulness and resilience in caring for younger siblings. Depending on the ages and circumstances of the children concerned, a child-headed household may be a better option than for children to be separated and absorbed into other households. However, lack of adequate support means older children are often providing care at the expense of their own education or future plans (Dorrington, et al, 2006).

According to Forster & Williamson (2000) the magnitude of the responsibility to raise siblings forces the children to take on an adult role and they have to grow up too quickly which companies difficulties of copying with their changed circumstances and the uncertainty of the future. The South African Department of Welfare has recognized the growing problem in child-headed households by changing the law to allow under age youth to access child support grants. However, the problem still exists because in order to

be successfully claiming these grants, children need important documentation (death certificate, identity document and birth certificate).

This is one of the reasons DOSD started funding home-community-based care and support programs that assists more than 200 000 children affected by HIV and AIDS. It also provides social support to child-headed households and assists a network of local childcare forums.

2.6. SOUTH AFRICA'S GOVERNMENT RESPONSE TO HIV/AIDS

In 1987, the apartheid government recognized that HIV and AIDS had the potential to become 'a major problem', even though there were few reported infections (Dorrington, et al 2006). The government's first significant response to AIDS came when Nelson Mandela addressed the newly formed National AIDS Convention of South Africa (NACOSA) in 1992. The purpose of NACOSA was to begin developing a national strategy to cope with AIDS. To address the HIV situation in South Africa, the government has drawn up a comprehensive National Strategic Plan that describes the roles that the different stakeholder should play in order to make a joint response to this challenge. CBOs are one such stakeholder playing key role in addressing HIV in South Africa. However, the CBOs experience financial and technical constraints in their efforts to provide HIV/AIDS services (AFSA, 2008).

The government of South Africa has developed various policies and guidelines to address HIV/AIDS pandemic. In response to the HIV/AIDS crisis, the Department of Social Development, in conjunction with the Department of Health and Education, designed the HIV/AIDS/STI Strategic Plan for South Africa 2000-2005(Government of South Africa). The approval of the new HIV & AIDS and STI Strategic Plan for South Africa 2007-2011 (NSP) by the SA Cabinet and the reconstituted South African National AIDS Council (SANAC) marked a major breakthrough in the response to HIV and AIDS.

Different researchers agree that the introduction of new HIV/AIDS and STI Strategic Plan for South Africa 2007-2011(NSP) flows from National Strategic Plan of 2000-2005, the Operational Plan for Comprehensive HIV and AIDS Care, Management, and treatment (CCMT) as well as other HIV and AIDS strategic frameworks developed for government and sectors of civil society in the past years represents the country 's multi-

sectoral response to the challenge with HIV infection and the wide-ranging impacts of Aids (Qubuda, 2009). Dorrington, et al (2006) agree that, the South African government and representatives of labor, civil society and the private sector, through SANAC, finalized a new Strategic Plan for HIV and AIDS and STIs in South Africa, for 2007 to 2011, which aims to cut new HIV infections by 50% and provide treatment to at least 80% of HIV-positive people by 2011.plan meets with wide national and international approval.

Dorrington, et al (2006) further highlighted that the South Africa government's response to the HIV and AIDS epidemic needs to be assessed and monitored against an ambitious but achievable National Strategic Plan, to which all role-players have committed themselves. The NSP commits government to funding non-government initiatives that are aligned to the key priorities of the plan. The NSP is founded on the need for partnership across all sectors and paved the way for improved cooperation between government and NGOs in terms of policy and service delivery.

One of the key priority area of NSP aims to reduce HIV infection and AIDS mobility and mortality as well as its socio-economic impact by providing appropriate packages of treatment, care and support to 80% of HIV positive people and their families by 2011.The NSP strategy consists of four major priority areas: prevention, treatment, care and support; research; monitoring and evaluation and human and legal rights. These objectives have been casted so that the resources required to achieve them can be budgeted. Action plans for their implementation, along with the lead agencies responsible, the indicators for success and the mechanisms for monitoring are spelled out. It is the responsibility of the Health Minister to keep this on track. It is the job of SANAC, in which every sector of society is represented, to hold government accountable for implementation of its plan (Dorrington, et al, 2006).

The National Integrated Plan for children and youth infected and affected by HIV/AIDS (NIP) is the government's strategy for managing the spread and impact of the disease. Within the NIP programs, the Departments of Social Development (DSD) and the Department of Health (DOH) are assigned the role of establishing Community-Home

Based Care Support programs and providing income and food support via poverty relief program.

2.7 THE OVERVIEW OF COMMUNITY-HOME BASED CARE (CHBC)

Community-home based care provide a comprehensive services, which include psychological, social, medical and nursing support to HIV-infected and affected persons and their families. It is seen by many countries as the only realistic approach to cope with the crisis (Van Dyk, 2005). Although community-home based care had been in existence long before the advent of HIV/AIDS. Community-Home Based care for people living with HIV and AIDS started in North America and Europe when it became clear that hospital care was too expensive, and those families and other care givers found it difficult to cope on their own with the demanding care of PLWHAS (Spier & Edwards, 1990).

According to Sims & Moss (1995) Community-Home-based care was introduced in a number of countries during the late 1980s and early 1990s.The main aim of introducing Community-home based care program was to decreased rehospitalisation, improved outpatient treatment procedures and to put more emphasis on home and community based services. WHO (2002) states that in Sub-Saharan Africa and other developing countries most Community Home Based Care programs were developed as unsystematic and need-based effort when it became evident that other option of care were necessary to deal with the effects of HIV/ AIDS .They were mainly initiated by Non-Governmental organizations (NGOs), and Community based Organizations (CBOs), Faith Based Organizations (FBOs) and concerned individuals.

These organizations had to invest time in maintaining the governmental relationships as a key element to the program's success. Even, now the major problem that most CHBC programs face is establishing and maintaining functional links and relationships with government structures and other related agencies. A number of other non-government as well as community organizations are involved in training community development workers and community volunteers to assist families with community- home care (Uys L, 2002). CHBC has always existed as an option to hospital-based care for terminally ill patients and it preferred because it gives the patient an opportunity to be supported by his or her family in a familiar and caring environment (Russell &Scheiner, 2000).

In response to this, government support for home and community-based careers employed by NGOs and CBOs has increased. The state has also promoted the training of lay counselors to promote voluntary HIV testing. There are many problems associated with it, including the poor remuneration and resourcing of CHWs, their 'Cinderella' status in the health sector and the uneven quality of the training they receive. Nevertheless, community and home-based carers have been the backbone of the response to HIV and AIDS.

A wide range of local, national and international NGOs have responded to the HIV and AIDS crisis facing South Africa. They are engaged in service delivery, including prevention, care and treatment programs, human rights work, including paralegal advice and litigation on behalf of people living with and affected by HIV and AIDS, and in research and education, advocacy and lobbying. Many NGOs have been established purely to address HIV and AIDS. Most NGOs working on other issues have integrated responses to the epidemic into their programmes. While this is a logical response, some HIV and AIDS interventions have been donor driven, since funds have been earmarked for HIV and AIDS in preference over other areas of need.

2.8   THE IMPACT OF COMMUNITY HOME -BASED CARE

Russell & Schneider (2000) state that an attempt to deal with impact, it is now common practice for health care facilities to ration services to people with HIV. Much of the burdens of HIV care in developing countries are now falling onto households and communities

In some instances there have been effort to develop alternative community based care structures; through programs such as home based care and hospices. Parallel to these initiatives, the growing number of AIDS orphans is causing some communities, community –based organizations (CBO) and non –governmental organization (NGO) to identify feasible strategies to protect and provide for the basic needs of this extremely vulnerable group. Presently the focus now is on how to achieve greater community participation in meeting the needs of people who are infected and affected by HIV/AIDS.

Russell & Schneider (2000) outline that much of recent literature on home-community based care and support has emerged in different countries like Botswana, Zimbabwe,

Zambia, Tanzania, Malawi, and Uganda. In these countries systematic efforts have been made to implement and evaluate community based activities since the late 1980s and include some of the well-known models such as Family Aids Caring Trust (Fact) in Zimbabwe and the Aids Support Organization (TASO) in Uganda.

Russell & Schneider (2000) contend that literature suggests that integrated community care and support strategies, as well as prevention within a continuum of care, can have a positive impact on mitigating and decreased the spread of HIV/AIDS. Community based services are more accessible to clients and families, decrease isolation, and provide needed interventions which can contribute to the quality of care for infected and affected people.

2.9 COMMUNITY INITIATIVES/RESPONSES TO HIV/AIDS

According to Centre for AIDS Development, Research and Evaluation (CADRE) (2005) there is a general consensus that CBOs and NGOs play an important role in helping families and communities cope with the impacts of HIV/AIDS, but that the approaches used often vary and are more difficult to systematize. In a study conducted by CADRE (2005) on Community responses to HIV/AIDS in South Africa highlighted that, these responses-which range from informal support group of relatives, neighbors, or church members, though to formalized community organizations that provide social services – are proliferating across the country. However, such initiatives are largely unknown outside their own localities, are inadequately recognized by policymakers, and are largely marginalizes from planning and funding systems.

Many researchers have stressed that there are compelling reasons to take closer look at community –level responses to HIV/AIDS –not least because these initiatives are and will almost certainly continue to be, a fundamental part of the way HIV/AIDS is lived and experienced at the local level. There is much we do not know about the extent, shape and impact of community responses to HIV/AIDS: What contributions are community initiatives actually making to the larger struggle against HIV/AIDS? What motivates individuals or groups to begin engaging with HIV/AIDS related issues in a public or collective way? Are there certain conditions under which community responses emerge

or flourish? Are there other ways that government or donors policies could better support and encourage such activity? Should they? (CADRE, 2005).

Goudge , Gilson , and Msimango (2003) support that on a conceptual level, community level responses are seen as immediate, direct and flexible, they emerged from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organizing and acting and draw up available resources. Forster and Williamson (2004) also maintains that although community level response often happens in a small scale in nature but their cumulative impact should not be underestimated.

According to Goudge, et al (2003) HIV/AIDS that have emerged organically at local level to cope with these Community level responses are seen as immediate, direct, and flexible, they emerge from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organizing and acting, and draw upon available resources. Forster (2004) maintains that although community level response often in a small scale in nature but their cumulative impact should not be underestimated. Birdsall and Kelly (2005) state that AIDS is an ecological crisis that affects all elements of society and the way if functions, with effects felt at the individual, households and community level. Communities are mobilizing and responding to aspects of the epidemic in a variety of ways, and a significant role is being played by non-state actors such as CSO. These grassroots responses exist in varying relationships with other HIV/AIDS initiatives including the more centralized response frameworks led by government in particular.

2.10   STUDIES ON COMMUNITY RESPONSES TO HIV/AIDS

Centre for AIDS Development, Research and Evaluation (CADRE) (2004) contends that there has been little systematic study of community responses to HIV/AIDS. Much of what is known is descriptive and comes from reports by non-profit organizations, development agencies and project managers working at community level. In many cases, these reports focus on particular types of response, such as programs for orphans and vulnerable children or home based care programs. Little if any research has been undertaken on quantifying community responses as a whole on exploring how they interface with other types of activities within a given community.

CADRE (2004) conducted an audit of local responses to HIV/AIDS in three local communities. Report further indicated that Local responses have always been overlooked and marginalized in favor of emphasis on large –scale centralized approaches to HIV/AIDS prevention, care and treatment. The main aim of the study was to explore the nature of local-level responses, the major actors involved with AIDS response at community level types of services being provided (and by whom), and the challenges being faced by local groups involved in AIDS response.

The study was conducted in three communities: Vosloorus (Johannesburg), Obanjeni (Kwa-Zulu Natal), and Grahamstown (Eastern Cape). The focus of questionnaires were on the organization itself (type, years in operation, staff, volunteers, financial management, etc); the areas of HIV/AIDS activity in which it is engaged, the types of services provided and successes and challenges encountered in AIDS response work. Additional in –depth interviews were conducted with selected key informants to better understand issues of co-ordination and integration of AIDS –related activities within participating communities. Another research conducted by CADRE (2004) highlighted that there has been a small number of attempts to assess community level responses to HIV/AIDS in Southern Africa. Although it should be noted that these vary greatly in focus, scale and approach. Nonetheless, the findings of these studies highlight some important dimensions of community responses and merit a brief overview.

In a rapid appraisal of community level care and support services available for PLWHA in South Africa, Russell and Schneider (2000) note that localized projects are emerging cross the country to fill the gaps in formal services, including support groups, outreach to OVC, and home based care. Russell and Schneider (2000) found that most of these initiatives are in their infancy and quite "precarious" operating with limited resources and little external support. They point out that there are guidelines or uniform standards relating to quality of care within the sector challenges include recruiting and managing volunteers and accessing resources. They note that, however that the most successful and sustainable initiatives were those that had established partnership and referral

relationships with other local programmes and that operated in communities with high levels of social cohesion.

A small-scale study in the Amajuba District Municipality in Kwa-Zulu Natal sought to identify the various types of child welfare organizations (including those providing OVC support that exist in the area and the services that they provide The research found that 25 different organization –predominantly CBOs and NGOs –that are involved with child welfare work. Despite the fact that these organizations work in the same municipality on the similar issues they are largely unaware of each other's work and tended to operate with professional networks. This proved that there was no forum or initiatives to coordinate the work of groups supporting OVC and people living with HIV/AIDS.

2.11 NATIONAL GUIDELINE ON HOME /COMMUNITY-BASED CARE MODEL

In South Africa the development of home based care model for supporting infected and affected people was the result of the pilot project in different communities. The project was designed to identify practical solutions to specific problems that HIV infected and affected people are facing. Thandukuphila was one of the pilot projects in Enseleni in Kwa-Zulu Natal.

According to the South African Guidelines on Home Based care and Community Based Care; Department of Health (2001) outlined that this type of de-institutionalized care addresses several problems, including: shortage of hospital beds, inadequate number of medical and allied health professionals in the public sector, the lack of resources for treatment and drugs, hospital overcrowding combined with staff shortages, which makes it difficult to manage patient with terminal illness, and high cost of institutional care. In order to provide appropriate care and support for people who are affected and infected by HIV /AIDS, especially in less developed countries with minimal resources and health budgets, a comprehensive integrated approach that addresses the medical, psychological, spiritual and emotional needs is necessary. Community based care, specifically in relation to HIV, includes any aspect of care along a continuum of illness, from the time a person is infected through the terminal illness. Care may continue in the form of counseling after the patient's death for those who are left behind.

This section gives outlines of the models of Community Based Care in South Africa as outlined by ICHC. It includes those addressing the needs of orphans. Departments of Health and of Social Development have suggested five models of care. These are the following:

i) Community –driven model

Department of Health's National Guidelines on Home Based Care and Community Based Care (2001) illustrates that community–driven model is based on integrated service provision locally–driven initiatives. This model could be attached to community structure. Community developer can liaise with other organizations and train volunteers. Community developer can also approach Government Departments or NGOs for resources.

ii) Formal Government sector model

In this model the community based care programs is coordinated at a district level by multidisciplinary team of doctors, nurses, and social workers within the hospital structure. It is led by departments such as Department of Health, and Welfare (Now Social Development) in collaboration with various sectorial partners. Professional nurse and community health care workers conduct home visits.

iii) Integrated home/community care Centre model

This model is structured around care centre which is located within the community. The Centre is run by volunteers; however, Departments of Health and Social Welfare may send professional nurse or a social worker to offer services. The Centre should offer various serviced including, pre-and post –test counseling, HIV testing, training of family members and community care givers as volunteers, facilitation of income generating projects, supervision and monitoring of community care givers, conducting of home visits and patient follow –ups and referral to and from hospital and other service providers. It could offer day care centre for infected and affected children.

Thandukuphila is a combination of different models but its main focus is on this model because it is a community program that integrates home based care and community based care. It renders services to different destitute people like orphans and vulnerable children, PLWHA, caregivers, and other people who are affected by HIV/AIDS. The centre is located within the community. It receives support from Department of Social Development, Department of Health, Department of Agriculture and Department of Education, Umhlathuze municipality, local clinic, hospital and other NGOs and businesses around Zululand.

iv) NGO home /community based care model

This model is similar to the previous model in that it is located within the community itself. The entire home based care program is initiated by a coordinating NGO.Needs are identified and services are provided by NGO, however, the home care program can be financially supported by the business and health sectors, social welfare organizations, other NGOs, CBOs and FBOs.The team may include a professional nurse or social worker, project coordinator and volunteers or community caregivers who are based at the NGO.

v) Integrated community and home based care (ICHC) model

The ICHC model emphasizes a continuum of care between all sectors of the health care system, and emphasizes palliative care. ICHC is similar to NGO model but has the additional benefit of being managed by an NGO that is already well established and self-supporting.

These models purport to incorporate all levels of society –the formal health sector, relevant NGOs/community-based organizations (CBOs), faith-based organizations (FBOs) and the community, and have the common goal of providing adequate care to patients and their families within the context of the community, taking into consideration socioeconomic conditions, need and constraints.

Uys (2003) emphasizes that in order to accommodate the social and economic diversity of communities, the integrated home-based care model links all the services provides with patients and their families in the continuum of care. The patient and family are

supported by a network of services such as community caregivers, clinics, hospital organization, NGOs and community -based organizations (CBO's) as well as by the larger community. This integrated model allows for referral between all parties as trust is built and it ensures that community caregivers are trained, supported and supervised. In the single-service home based care model, one service provider (usually a clinic, hospital, NGO, or church) organizes home based care by recruiting and training volunteers and brings them into contact with patients and their families at home.

Uys (2003) further mentions that many Home Base Care Programs start this way and build their way up to offer-integrated care as they recruit other parties. In the informal home based care setting families care for their sick loved ones at home, with the informal assistance of their own social network. Nobody has any specific training or external support and there is no formal organization or supervision of the care. Informal care can be very difficult because the primary care giver often lacks the necessary knowledge, skills and emotional support needed to care for an Aids patient. According to Uys (2003) the integrated HBC model is the ideal model for quality physical care and psychosocial support for the person living with Aids and his/her family.

2.12 INTEGRATED COMMUNITY BASED CARE (ICHC) MODEL

In South Africa there is a National Community Home Based Care service model known as Integrated Community Based Care (ICHC) model running in about seven sites in different provinces. The Department of Health in conjunction with Department of Social Welfare and Development has developed National Guidelines for CHBC to guide the implementation of Community Home- Based Care in the South Africa. In 1999 Policy Project supported seven hospices to incorporate the Integrated Community Based Home Care (ICHC) model into their operational activities. Different similarities and differences of the various models of Home and Community Based Care were identified. Field research was conducted by CRADE at seven sites in different hospices in five provinces including. Kwa Zulu Natal, Western Cape, Free State, Gauteng and Eastern Cape during April and May 2002 (Fox, et al 2002).

In 1997, the South Coast Hospice was the first hospice to implement the ICHC model by the department of health through the USAID –funded policy project as an extension of the hospices experience in palliative care and outreach activity. Two years later the Department of Health provided funding to HASA to manage the implementation of the ICHC model into the operation activities of seven hospices around the country. Pilot projects were established in Bloemfontein, Port Elizabeth, East London, Empangeni, Pretoria, Port Shepstone, and Somerset West.

The ICHC model sets out to provide the best quality of life for patients and their families (ICHC 2005), as can be seen in the model, the core of programs is the person with terminal illness and that persons 's family, as such, reflects a patient –centered approach. The core is then supported by the micro –community, including neighbors, extended family and various agencies including the formal health care sector, community-based organization and hospice that are also focused on caring for the patient and family. This represents the continuum of care and support for patients.

The characteristics of this model include: a shift from relying on the care of professional nurses to community based caregivers, and from institutionalized setting to home care, a focus on both the patient and the family and emphasis on education with the aim of decreasing the transmission of HIV by empowering families and the community with knowledge and skills. Hospice provides the overall management of home-based care programs as well as various forms of support through the existing hospice structure to assist the program. Ncama (2005) evaluated and analyzed ICHC to assess and ascertain to what degree the outcome meets its own claims .She found that the ICHC model provides an integrated approach to the management of HIV/AIDS through its palliative care programme.

2.13   HOME-BASED CARE

Home- based care is an aspect of community- based care that focuses primarily on physical /medical and palliative care of the patient at home, with the support of family and the immediate community (Russell &Schneider, 2000). WHO (2001) defines Home Care as the provision of health services by formal and informal caregivers in the home in order to promote restore and maintain a persons maximum level of comfort, function and

health including care towards a dignified death. WHO (2001) further identifies the following as the goal and objectives of the Home Based Care programs.

Home -based care provides an alternative to institutionalized health care, and has received greater emphasis with the advent of HIV/AIDS (World Health Organization, 2001) Community care is usually based outside formal health facilities, but is built on partnerships with formal government sectors, such as health, welfare and development sectors. Both community and home –based care are essential in providing comprehensive and continual care for patients and their families within their communities. The main goal of the Home -Based Care is to provide the organizational structures, resources and framework that will enable the family to look after its own sick members.

Functions of Home Based Care programs include empowering the community/ family to cope effectively and the physical, psychosocial and spiritual needs of those living with HIV infection and Aids, to support family members in their care giving roles, and to reduce the social and personal impact that living with HIV infection and AIDS makes on all those concerned, to establish a well-functioning referral system to hospitals, hospices, clinics and other health care facilities in the community and to ensure that children and families who are affected by HIV/AIDS access social welfare services within their communities.

2.13.1 ADVANTAGES OF HOME BASED CARE

Home -based care and support, capacitates and mobilizes communities to mitigate the effects of HIV/AIDS. The model does not imply shifting the burden to communities but its intention is to ensure that persons who are infected and affected by HIV/AIDS have access to integrated services that address their basic needs for food, shelter, education, health care, family or alternative care and protection from abuse and maltreatment. Good basic care can be given successfully provided in the home. People who are very sick or dying often prefer to stay at home so that they can spend their last days in family surroundings, especially when they know that they cannot be cured in hospitals. Sick people are comforted by being in their own homes and communities with family and friends around them. Home based Care also prevents the patient from feeling isolated and rejected. If the sick person is at home, family members can attend to other responsibilities

more easily. It also encourages family and community involvement in the care of their own members creates general Aids awareness in the community and this helps to break down fear, ignorance, prejudice and negative attitudes towards people with Aids. (Froehlich, 1999)(Uys, 2003).

Russell &Schneider, (2001) add that CHBC has been found to be the best method to care for many people with terminal illness because the extended family has been the traditional caring unit in society. It would in most cases be available and share responsibility for care with professionals.

2.13.2 PRINCIPLES GUIDING HOME -BASED CARE

The impact of HIV/AIDS on families and children is understood within the context of the community, taking into consideration their specific socio-economic conditions, felt needs, constraints and possibilities. Home-based care is person-centred, sensitive to culture, religion and value systems but respect privacy and dignity (community-driven, customer-driven). Activities are planned, implemented, monitored and evaluated with the community and not for them. Networking of various community-based organizations in the community to provide holistic services to children and their families is facilitated.

2.13.3 THE ROLE OF VOLUNTEERS IN A HOME/COMMUNITY   BASED CARE PROGRAM.

Community-based care relies on volunteers to provide emotional and practical support to household that are providing palliative care to sick and dying relatives. According to Marston (2003) local community volunteers play a very important role in home-based care program. Volunteers usually come from a variety of backgrounds and they may be trained and experienced professionals, trainee community caregivers, family members or compassionate community members who wish to help those in need. Volunteers should never be expected to offer HBC without a good basic training and understanding of physical, psychosocial emotional and spiritual conditions if they may encounter and how to deal with these.

In a study conducted by Russell and Schneider (2000) showed that programs with inadequate or no funding found it difficult to maintain volunteer commitment in community based care programs. There is a high turnover of volunteers who once trained and without contracts, may withdraw their help at anytime and move to other opportunities. Organizations with successful programs tend to recruit those who are well respected in the community, as well as provide some form of incentive, ranging from a monthly stipend or other small incentive.

Some innovative in South Africa reward volunteers by offering them some form of skills training program that may generate work opportunities for them in future such as computer/driving courses donated by companies in the community. However, it also not easy to ask people who are living in desperate poverty to work for free. This is the case with Thandukuphila Community Based Care Centre. Volunteers receive R 500.00 stipends only and sometimes difficult for them to render programmes effectively; in spite of this many volunteers value the skills that they acquire through volunteer work.

Uys (2003:5) points that volunteers work hand in hand with home-based care givers and both of them are also in the ideal position to identify the needs of children who are affected by the illness issues such as whether the child is attending school or not, whether the child has time to play. They are also in the position to know who supports the child psychologically and emotionally; whether the child understands what is going on in the family' and will look after the child after the death of the parent.

2.14 SUMMARY

Available literature has been reviewed which includes several studies conducted on community initiatives for HIV/AIDS infected and affected people including children. What other researchers have written will form basis when analyzing the findings of the study.

CHAPTER THREE

3. COMMUNITY PROFILE THANDUKUPHILA COMMUNITY BASED CARE CENTRE

3.1   INTRODUCTION

Community profiling is an analytical tool for community development. This chapter looks at the community profile of Thandukuphila Community Based Care Centre. This organization is the first of its kind at this community and area. It is a developmental community venture that has significant import for the welfare and the lives of the categories of people who need the type/s of services it was established for.

The Centre has the following objectives to achieve:

(a)To restore Human dignity to those who are infected and affected by HIV/AIDS.

(b) To decrease the spread of HIV/AIDS in the community

(c) To care for HIV/AIDS orphans

(d) To develop poverty alleviation projects in the community

(e) To develop income generating projects in the community.

This project is an integrated approach not fragmented departmental initiative. Each department has its own mandate. It is an integrated answer to needs of local communities, households and individuals infected and affected by HIV/AIDS.

- Department of Social Development provides services to orphans and vulnerable children (care & support)

- Department of Education provides school based program (life skills) management and prevention of HIV/AIDS.

- Department of Health provides care and support, testing and counselors health management and prevention.

- Department of Agriculture provides youth and support group with starter kit for gardening projects

3.2   HISTORICAL DEVELOPMENT OF THE PROJECT

Historically, the province of KwaZulu-Natal (KZN) has had disproportionately high levels of poverty, particularly, in rural areas. While the national population is split almost evenly between urban and non-urban areas, the proportion in population living in non-urban areas is considered to be approximately 56% in KwaZulu-Natal. The now existence or collapse of rural economy has also caused high levels of migration to urban centres resulting rapid development of informal settlements with minimal services on the periphery of towns like Richards bay.

Thandukuphila Community Based Care Centre is a community-based organization (CBO) for HIV/AIDS infected and affected people of Enseleni and surroundings. Enseleni Township was established in 1979 is one of former KwaZulu government townships. Spoornet (former SA railways) established this township with the aim of building compounds or hostels for people who were working at Richards Bay Terminal. Later it was erected for poor people from various areas seeking employment. Most of the people in this area are working at Richards Bay contractors and companies. Enseleni is the nearest township to Richards Bay.

Thandukuphila is situated at Enseleni Township, just outside the town of Richard bay. It is located in North Coast Region. It is under KZ292 categorization. This is a semi-urban and rural area. The district council of this area is UThungulu Municipality and the local municipality is UMhlathuze. Enseleni has a population of about -+200000 occupying approximately, 1578 houses (Umhlathuze municipality, April 2004:11) there is a high rate of unemployment, illiteracy and poverty in this area.

3.3   FACTORS CONTRIBUTING TO THE SPREAD OF HIV AIDS

The following factors are contributing to the rapid spread of HIV/AIDS within the area Enseleni:

Migrant labor system created by apartheid contributed to the spread of HIV/AIDS, because it produces a situation where men are obliged to leave their homes to reside in single hostels. The non-existence or collapse of the rural economy has also caused high levels of migration to urban areas resulting rapid development of informal settlement within minimal services on the periphery of Enseleni Township.

- Rapid urbanization leading to the breakdown of traditional social mechanism of control for social and sexual behavior.

- Political and factional conflicts between the mid 1980s to mid 1990s have also contributed to poverty and migration out of conflict- ridden communities and into communities perceived to be politically or factionally homogeneous.

It is within this context that HIV/ Aids have grown to pandemic levels. This area is said to be the epicentre of HIV/AIDS pandemic. This centre was established as a response to the need of support for desperate and destitute community of Enseleni.

3.4   PROJECT INCEPTION AND HISTORY OF THE PROJECT

The project was initiated due to the high prevalence of HIV/AIDS in Enseleni Township and surroundings. Concerned Catholic Church volunteers who were trained by Ngwelezane hospital as caregivers started this project during the year 1996. They saw their friends and neighbors dying of HIV/AIDS with neither government nor community support. During their visit they discover that in some families the breadwinner is the one who is terminally ill from HIV/AIDS and family starving. Children were orphaned and headed some families, as both parents were deceased.

The volunteers used to take food from their homes and even give the family money to take the sick person to hospital. The volunteers then decided to do something to generate income. They involved primary caregivers (members who are affected) and they started knitting, sewing, gardening and poultry project. They wrote to different churches for funding. Churches gave them material. Products were sold and money was used to buy food, buy medication and take sick people to hospital as well as school fees for children. In 2000 Department of Health and Department of Welfare offered their support and Thandukuphila was formally established. This facility started off as a crèche for infected and affected children and later develop into what it is today community base care centre.

Enseleni has a high prevalence of HIV/AIDS. Thandukuphila community based care centre was approached by the department of Welfare to initiate Drop-in centre for children and youth affected by HIV/AIDS. This community based care support centre is providing integrated services to those infected and affected by HIV/AIDS. This is an

essential resource in the community. This centre adopted the holistic approach that encompasses the emotional, social, psychological, physical and spiritual needs of its beneficiaries. It also uses multi-dimensional approach to community care and support.

3.5   BENEFICIARIES OR TARGET GROUPS OF THE PROJECT

- This include children whose primary care givers are HIV positive (i.e. children who are at risk of becoming orphans);

- HIV/AIDS positive children;

- Children whose caregivers are in advanced stage of the disease,

- Children headed household;

- People who are living with HIV/AIDS;

- HIV/AIDS affected and infected youth and

- Infected and affected families.

3.6   SERVICES RENDERED BY THE CENTRE

3.6.1 Orphans Care and Support

Orphans and Vulnerable Children are identified by volunteer caregivers, community leaders and referred to Thandukuphila.They come for breakfast before they go to school and after school they come for lunch. Caregivers also assist them with homework after school. They are given and supported by food parcels twice a month. School fees are paid; school uniform and stationery are bought for those who are needy.

3.6.2 Activities for Children

After school care programme for (OVC) has life skills development program. They do different activities like beadwork, craft, cards, and painting. During the school holiday children attend Youth holiday Program that teach them about life skills, and life orientation. The children are also involved in the gardening project.

3.6.3 Day care facility

Children that are underage to go to school are cared for during the day. Most of them are HIV positive. They are given nutri-boost as most of them are on ARVs treatment. They are taken to the community health centre for their medication and vaccination, and to the hospital for their treatment.

3.6.4 Child and Youth Care Workers (Usibindi)

They work directly with children and their families. When they do not have the required documents to access the foster care grants and Birth Certificates or Death certificates for their parents as most of them died while they didn't have the ID books. They also do family conversing and advocating for the children, do the school visit to see how the children are going at school. They also have Safe Park where children are doing different activities and games.

3.6.5 Home base Care

There are volunteer/caregivers who are trained on Home Based Care, DOTS, ARVs, and child and youth care. They do home visits to clients, train the primary caregivers on how to care, bath and feed the sick person. They do have workshops with neighbors an opportunistic infections and how to prevent them. They also distribute condoms and pamphlets.

3.6.6 Support Group for PLWA

There is a support group for infected people. They meet once a week and share their experiences, support each other and come for ongoing counseling. They are educated and supported on how to live positively and on ARVs .The do income-generating project such as beadwork, sewing etc. They have vegetable garden. They also do public talks on HIV/AIDS.

3.6.7 The Luncheon Club

The organization has a luncheon club for senior citizens who meet twice a week. They have three groups, one meet at the centre, and the second one meet at the community hall at Kwa Bhejane Tribal Authority and in one of the villages. They also have exercises, share their experiences, do some sewing, beadwork and also working in the garden.

3.6.8 The Satellite Centre

As some of the OVCs that need the services that we are providing yet, they could not reach the main drop in centre. A satellite centre was initiated in Mayeni Village in the Tribal Authority to provide the same services as the main Thandukuphila Drop in centre for those OVCs within the Kwa Bhejane Tribal Villages. The satellite has 6 volunteer staff that helps out in providing services such as cooking, Day Care (Early Childhood Development Program) after school care program.

3.6.9 Income Generating Projects

Development and support services are provided to affected families in terms of income generating projects. There is a big vegetable garden and the land for the garden was donated by Inkosi (local leader of Nseleni Tribal Area). There are 20 members who are involved in the garden project and they each get a stipend of R100.00 a month from Social Development, vegetables that they grow are used to cook for the OVC's and also give to the needy families.

3.6.10 The Food emergency Program

The organization cooks two meals per day for the sick and needy clients seven days a week and delivers to those who cannot collect for themselves.

The centre also renders the following services: Pre and post test counseling home- based care, awareness campaigns, education and training on home based care and caring for OVC, skills training and development program e.g. sewing, gardening, fundraising skills, etc.

3.7 OTHER SERVICES RENDERED BY THE CENTRE

Pre and post test counseling, home based care, awareness campaigns, education and training on home based care and caring for OVC, skills training and development program e.g. sewing, gardening, fundraising skills etc, food parcels, day care for under age children, breakfast and lunch for school going children.

3.8 NETWORKING

Thandukuphila is currently networking with other NGO's and CBOs working in the HIV/AIDS field so as to provide services required by communities in partnership with other organizations. The centres currently work closely with Qalakahle unisex club, which cares for HIV/AIDS orphans as well as homeless children. The centre also works with Phumelobala Aids program that provides home-based care whereby they bath and feed sick people.

3.9 CHALLENGES

First and foremost the researcher clarifies that the organization operates in a tribal semi-rural area. Such areas have been bypassed by infrastructural development, socio-economical development experienced by counterparts in urban and metropolitan areas. Hence Thandukuphila as an organization operates with some limitations.

There is a lack of full community participation especially local community stakeholders such as churches, government sectors, private sectors, community organizations. There is no forum where community discuss issued related to service delivery. The researcher thinks that if different community stakeholders meet on regular bases, Thandukuphila could improve its service delivery to the beneficiaries and community as a whole.

There is no system in place to identify Orphans and Vulnerable Children (OVC) and people living with HIV/AIDS. There is no shelter for destitute and homeless children. They refer children to place of safety which sometimes becomes difficult.

The researcher established that although this centre receives help from the government, but officials are doing little to monitor and evaluate service rendered to ensure effective service delivery. The centre does not have full time social worker to assist caregivers and volunteers with guidance on placement of children in foster care and government grants to needy people. Presently she comes once a week which is not enough.

Lack of funding from a government department and proper training of committee members pose a threat to the success of this centre government should provide sufficient financial budget to Community -Based Care Centre, train committee members on

financial management and management of organization, because if people are not train it is difficult to utilize funds accordingly.

3.10 SUMMARY

In this chapter community profile of Thandukuphila Community Based Centre has been discussed. The discussion has highlighted the historical development of the centre, its objectives, services rendered and challenges that are faced by this centre.

CHAPTER FOUR

4. RESEARCH DESIGN AND METHODOLOGY

4.1   INTRODUCTION

In this chapter aspects related to the research design population, sample, pilot study, biographical data, data collection method, transcribing of data, data analysis and ethical considerations are discussed.

4.2   RESEARCH DESIGN

This involves a scientific work that is adequately planned, with a well-defined methodology. This assists the researcher to obtain the intended and convincing results. Polit et al, (2004) define this process of research design as the general plan for obtaining answers with regard to the issues being studied. For this study a qualitative research approach that is explorative and descriptive was used to determine the impact of Thandukuphila Community Based Care Centre to beneficiaries.

4.2.1 EXPLORATORY DESIGN

Exploratory research was conducted to gain insight into a situation, phenomenon, community or individual. It aims at gaining familiarity with a phenomenon or achieving new insights into it, in order to formulate a more precise problem or to develop hypotheses. Generally, exploratory research has a basic research goal and researchers frequently use qualitative data to obtain an inside perspective on social action (Babbie and Mouton, 2004).

Babbie (2004:90) outlines three purposes of the exploratory study

1. To satisfy the researcher's curiosity and desire for better understanding of the problem;

2. To test the feasibility of the study being undertaken; and

3. To develop methods to be employed in a more careful manner.

4.2.2 DESCRIPTIVE DESIGN

According to Sarantakos (2005) descriptive research design is quite common, in most cases as a preliminary study. It aims to describe social systems, relations or events, providing background information about the issues in question as well as stimulating explanations. Descriptive research presents a picture of the specific details of a situation, social setting or relationship, and focuses on how and why questions.

4.3   QUALITATIVE RESEARCH METHODS

The study adopted a qualitative research approach because it studied events in their own natural setting (McMillan &Schumacher 1993) (Creswell 1994). Strauss & Corbin (1990: 17) further indicate that qualitative research refers to the research about the people's lives beliefs, and behavior).Fraekel & Wallen (1990:37) add that qualitative research is concerned about the quality of particular activity than how often it occurs.

This makes possible to gain both depth and detailed information concerning the phenomenon of interest without manipulating the research setting (Strauss &Corbin, 1990). Exploratory research was conducted to gain insight into a situation, phenomenon, community or individual. Generally exploratory research has a basic research goal and researchers frequently use qualitative data to obtain an inside perspective on social action (Babbie and Mouton, 2004).

Qualitative research enables the researcher to study human action and interaction from the perspective of participants themselves (Babbie & Mouton, 2004). Thus, qualitative research method was appropriate for this study since the aim was to determine the impact, the value and indeed the benefit, of Thandukuphila Community Based Care Programs, on the people, that live in the community of Enseleni and surrounding adjacent areas which are infected and affected by HIV/AIDS. It further explores the experiences and perceptions of beneficiaries of the programs in order to understand the dynamics of the circumstances involved from the participant's point of view as they live, interact and battle with issues affecting their survival.

4.4   DELIMINATION OF THE INVESTIGATION

The research investigation was limited geographically to Enseleni Township and surrounding areas, a rural area in the North Coast of the province of KwaZulu-Natal, situated almost twenty (20) kilometers, west from the big town of Richards Bay, a bulk exporting town with the second biggest harbor in the province.

Under the old Apartheid era administration, the area being rural in tribal land was administered separately from Richards Bay. Hence it never shared in the entire infrastructural development of the region, besides being one of the labour supplying areas to the burgeoning towns of Richards Bay and Empangeni. In terms of socio-economic characteristics is like most of rural areas in tribal land that are fast changing and 'transforming' in physical accommodation, with most houses now built in semi-substantial type buildings different from the small thatched one of the past. There are now roads in certain parts as well as electrical power enjoyed, of course, by a very few. There are schools, although most of the educators come from outside. This is the case in so far as the health facility such as the clinic and health personnel that deal with community health matters.

In terms of target subjects the focus is to assess the impact of the newly built (2000) Thandukuphila Community -Based Care Centre to the community with specially reference to the beneficiaries, the people who are infected and affected with the HIV/AIDS virus. Therefore, the research population consists of all the people who are involved in this centre and those who are service beneficiaries of its programmes, such as people living with aids-PLWA, orphans and vulnerable children-OVC, trained caregivers and volunteers from the community as well as committee members.

4.5   POPULATION AND SAMPLE

According to Strydom and Venter (2002) a population refers to individuals in the universe, who possess specific characteristics. Silva et al (2001) also makes the same reference to the definition that a population (or universe of research) as the total number of individuals, who have the same definable characteristics for a specific study.

Silva et al (2001) define sample as part of the population or the universe selected according to a rule or plan designed by the researcher in a disciplined and objective manner. It is not haphazard. A non-probability sampling procedure was followed. It is acknowledged that since this sampling procedure relies on available subject, and as Babbie and Mouton (2003:166), 'in some location;' it is acknowledged that it might be a risky sampling method. However, as these authors say, "It is justified only if the researcher wants to study the characteristics of people passing the sampling point at specified times….".Also the ease and inexpensive nature of this method explains its popularity.

A purposive sampling technique was employed to reach the participants. Purposeful sampling involves identifying individuals who will generate rich descriptions of the phenomenon. A purposive sample of nine participants from Thandukuphila Community Based Organisation which is situated at Enseleni was purposefully selected for the study. All participants were beneficiaries of Thandukuphila Community based care centre. According to Patton (1997) qualitative research makes use of a small number of cases to study a phenomenon in depth. All participants were African, Zulu-speaking, those infected and affected by HIV/AIDS and living in Enseleni and surroundings. These individuals were identified for their potential to elicit valuable information since they are beneficiaries of the programme. The individuals were also identified according to the criteria for inclusion. There were four groups of participants [i) PLWA, ii) OVC, iii) Caregivers/Volunteers, iv) Committee members]. Criteria for inclusion were the following:

- People Living with HIV/AIDS,

- Caregivers/Volunteers,

- Orphans and Vulnerable Children,

- Committee member/Supervisor,

- Beneficiaries of Thandukuphila CBC,

- Infected and affected people and

- Those willing to be interviewed by the researcher about their situation and issues related to the functioning and service delivery of the Centre.

Greeff (2002:292) alludes, to one of the challenges facing researchers when they do qualitative research interviews as establishing rapport. Individuals who were identified were approached and their interest in being involved in the study was explored. Introductory visits were made to the respondents to discuss the purpose and process of the sessions and obtain permission and cooperation from respondents to participate in the study.

The purpose of the visits was for the researcher to meet potential participants and inform them in more depth regarding the study. During such meetings the participant were presented with a research package, consisting of a standard letter, informed consent form, and an interview questions. The standard letter explained the nature of the study and invited the beneficiaries of Thandukuphila Community -Based Care Centre to participate in the study. Upon agreeing to participate in the study, the participant signed the informed consent form.

4.6 ETHICAL CONSIDERATIONS

A study of people who are infected and affected by HIV/AIDS needs to be approached with great sensitivity. The stigma of HIV is such that HIV positive people or those who have relatives that are HIV positive, interviewees may fear discrimination, rejection or even violence if their HIV status is revealed. Research on HIV explores the most intimate sphere of a person's private life. An interview can become a difficult and emotional experience, regardless of how well a person seems to be coping.

Morse and Richards (2002:205) identify the following ethical principles regarding participants' rights:

The right to be informed of the purpose of the study as well as what is expected during the research process. The amount of participation and time required. What information would be obtained and who would have access to it. Finally it should have what the information would be used for.

This would also entail the following:

- the right to confidentiality and anonymity.

- the right to ask questions of the researcher.

- the right to refuse to answer questions the researcher may ask, without negative ramifications, and

- the right to withdraw from the study at any time without negative implications.

The study adhered to these ethical specifications. Permission to conduct research was obtained from the participants. The researcher met each participant personally and spoke with him or her about the research, informing him or her of the purpose of the study. A letter was presented explaining the aims of the study and what would be expected from participants. Zulu was the first language of all participants; therefore, a translator was not needed as the researcher is fluent in speaking the language. The letter was distributed to all participants and was read through with participants who were capable of reading. Participants were given time to ask questions. The letter informed participants of the amount of participation and time required. Participants entailed, answering an interview questions, and signing a consent form agreeing to participate in the study. Participants were informed that each session would be between 30 and 60 minutes, would be audio-taped and then transcribed. Participants were made aware that findings would be presented in the form of a paper handed in for examination. Confidentiality and anonymity was guaranteed. Participants were informed that they would be given a code name to ensure their privacy.

The study posed no risk to participants physically. Due to the sensitive nature and complexities of people who are beneficiaries of HIV/AIDS programmes and emotions that may have been evoked during the interview, counseling services was made available since researcher is a social worker, this have been warranted. None of the participants requested or required counseling or debriefing following the interviews. Ethical clearance was obtained from the Thandukuphila Community- Based Care Centre, from the Ethical Review Committee and the Research Committee of the University of Zululand. It was important to ensure during the recruitment process that participants understand what their participation in the study would involve. Information about the research, as well as the

consent forms was written and explained in Zulu, and a written consent forms were obtained from each participant. They participated voluntarily, and were informed that they could withdraw from the study at anytime should they so wish. The ethical concern of the research was extended beyond confidentiality to a desire to provide a supportive environment for participants.

4.7 THE PILOT STUDY

De Vos (1998) defines a pilot study as a process that can be viewed as a "dress rehearsal" of the main investigation. It has the same essential features as the planned investigation but on smaller scale. The essential aspect is to test the understanding the potential respondent would make of the question, that is, their fair understanding of what is being communicated and elicited. Among the most common problems are that the respondent may consider some questions redundant, find some answer categories inadequate, and object to the manner in which some questions are worded. All this assists the researcher's effort in achieving validity and reliability.

The pilot study was conducted in the same manner as the final or actual study. During the interview the researcher probed for the respondents' understanding of the various questions. The time taken ranged between twenty five and thirty five minutes' per respondent. It involved two respondents. The following remarks were noted as elicited from these testing respondents:

- The content was relevant to the information required.

- The length of the interview schedule was reasonably satisfactory.

- Some of the questions were queried had to be rephrased.

4.8 VALIDITY AND RELIABILITY

Validity and reliability were addressed using criteria appropriate for qualitative research. As a validity check, themes were presented to several independent professionals that are working in the Community Home -Based Care Centre programmes as well as the HIV/AIDS programmes, these included Community Home Based Coordinators, Home Based Workers.

In the main, however, this process concentrated on the research instruments.

Validity refers to the degree to which an instrument measures what it is supposed to measure. Reliability, on the other hand, refers to the accuracy and consistency of an instrument. The reliability and validity of an instrument are not totally independent qualities of an instrument, a measuring device that is found to be unreliable cannot possibly be valid. This process was, therefore, aimed at ensuring that the questions would enable the researcher to meet the objects of the study.

4.9 DATA COLLECTION

Polit et al (2004: 53) define the instrument as the means of collecting precise information relevant to the objectives of the study. The collection of data is related to the problem, hypothesis or suppositions of the research and aims to obtain elements so that the objectives proposed in the research may be achieved (Silva, et al 2001). According to Leedy (1993:139) all data, all factual information, and all human knowledge must ultimately reach the researcher either as words or numbers. In qualitative research the researcher is the instrument of data collection and the credibility of the data collected is dependent on the skill of the researcher (Strauss &Corbin, 1990). Different data collection methods can be employed depending on the field of interest, as well as how much information is required.

In this study data was collected by structured, in-depth, face-to-face interviews. The purpose of this approach was to elicit the participants' perspectives with as few probes as possible. Interviews lasted from one and a half to two hours. The in-depth interviews involved one-on-one, face-to-face interaction between an interviewer and the interviewee. The researcher personally conducted all the interviews. In–depth interviews were utilized to seek deep information and knowledge regarding the experiences of people who are beneficiaries of Thandukuphila.

4.10 DATA ANALYSIS

Data analysis is the process of bringing order, structure and meaning to the mass of collected data (De Vos et al, 2002). Polit et al (2004) point out that it is in this phase that

the data is presented, interpreted, discussed and generalized. Qualitative researchers collect data in the form of written or spoken language or in the form that is recorded in language and then analyze the data by identifying and categorizing themes (Durrheim & Lindegger, 1999). Data analysis involves breaking up data into manageable themes, patterns and trends. The aim of data analysis is to determine whether any patterns or trends can be identified or isolated, or to establish themes in the data (Mouton, 2001). As a first step of the analysis process all interviews were audio-taped, transcribed, and subjected to qualitative data analysis.

Transcription and analysis of the interviews began immediately following the first interview and was preceded by analyzing the transcribed interviews, line by line, highlighting important ideas and themes. Verbatim transcripts were then analyzed by means of thematic content analysis. Thematic content analysis is a process of breaking down the text into themes and categorizing the patterns in the data (Durrheim, 2002).

4.11 TRANSCRIBING THE DATA

 An English speaking colleague helped the researcher to translate from isi-Zulu to English as English is my second language. This colleague validated that the translation was accurate. Interviews were then transcribed word for word from the audiotapes. The researcher transcribed one of the interviews herself to familiarize herself, with the process. The rest were transcribed professionally. The Zulu interviews were translated into English and only the English translation was transcribed.

4.12 PRESENTATION OF DATA

Accurate presentation of the data and findings is a way that captured the essence of the experience of beneficiaries of Thandukuphila Community Based Care Centre. In presenting the results, the research returned to the voices of the participants to describe their experiences of being beneficiaries.

4.13 SUMMARY

In summary, this chapter has presented the research design of the study. Methodological procedures were explored and undertaken in line with a qualitative research paradigm that was more suitable for the study. Ethical issues have also been discussed and the

research process explained in detail. In the following chapter the findings of the research will be presented in themes, categories as planned in the research procedures earlier on. Different categories was characteristic of the sections from which information was elicited, from the data as constituent aspects of the impact of Thandukuphila Community -Based Care Centre in the lives of people who are infected and affected by HIV/AIDS.

CHAPTER FIVE

5. PRESENTATION AND DISCUSSION OF THE FINDINGS

5.1 INTRODUCTION

The research findings presented in this chapter for discussions pertain to the impact the Thandukuphila Community Based Centre has in the community where it operates. According to the field research program, the research instruments were used to elicit information and views of the participants structured into for parts. This was done in order to have a specific one for each of the categories. It should be clear that all were mutually inclusive.

A qualitative approach was decided upon to be appropriate for the investigation. Qualitative studies do rely on participant observation and methods and believe that they are the best informers about the situation. This chapter includes data presentation, analysis, interpretation and discussion of the findings. In-depth interviews were conducted and recorded in the respective wards of the participants. Structured interviews guided the collection of data from participants.

For clarity in chapter three, it was indicated that in the sample four groups and/or categories were recognized that cover the entire spectrum and work of the Centre as at present. Hence these formed the basis of the sample from which most of the information was collected. Characteristically the sample consisted of adults both male and female and children of both sexes most of whom were school- going age. In the four categories the following were included:

- People Living with HIV/AIDS;

- Caregiver/Volunteers;

- Orphans and Vulnerable Children;

- Committee members and Supervisor;

- Beneficiaries of Thandukuphila Community Care -Based Centre;

- Infected and affected people and

- People willing to be interviewed by the researcher

A prior personal survey of the Centre and observation of what was going on as it presented and informed the researcher that these could form the base sample.

The researcher emphasizes that the interviews involved mainly one-on-one in face-to-face interaction between the interviewer and interviewee. It must be emphasized that the method employed with the interview guide allowed the researcher scope to listen, record and write. This enabled the Researcher, for instance to illicit the lived experiences of the interviewees. Hence this presentation will reflect the 'voices' of the participants as they described their experiences, expressed the hopes and frustrations as well.

5.2   BIOGRAPHICAL DATA OF PARTICIPANTS

The biographical data reflects the respondents group's age, gender and duration of involvement of all respondents in Thandukuphila Community Based Care Centre

5.2.1 GENDER

The gender of the respondent group (n=9) is indicated in figure 1.1
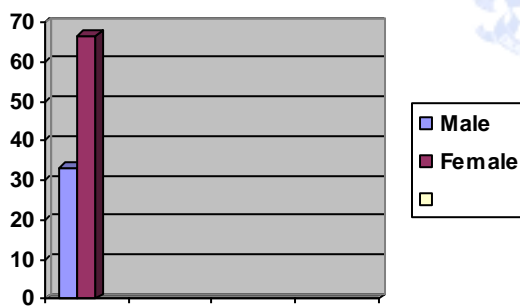
Figure 1.1 Gender of the participant group

It is obvious from the above figure that most of the respondents in this program were females. Out of nine (9) participants interviewed in the study, a three were male while six were females. UNAIDS report on the Global HIV/AIDS,(2006), states the view that the burden of dealing with the "fall out" of the epidemic rests particularly with women. Women are extremely vulnerable to the effect of the epidemic. However, this profile does not represent the gender profile of all Thandukuphila beneficiaries.

5.2.2 THE AGE PROFILE OF THE PARTICIPANTS

The age distribution of participants is reflected in figure 3.2
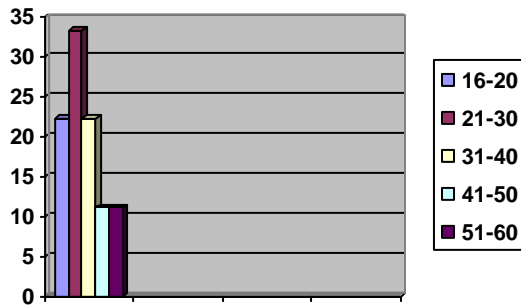
Figure 1.2 Participants age distribution

Figure 1.2 indicates that people who are most infected and affected by HIV/AIDS were between the ages of 21-30(young adult). Many authors concur that youth are most affected by this pandemic**.**

5.2.3 DURATION IN THE PROGRAM

The involvement of the participants in Thandukuphila Community Program

Is reflected in Figure 1.3
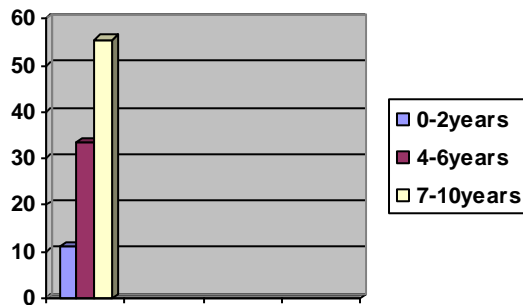
Figure 1.3 Participants duration in the program

It is evident from the figure above that most of the participants have been in the program for more than seven years. This figure correlates with the duration of the program itself, since this Centre was established in 1996. Most participants were more experienced in

identifying the benefits of the program for infected and affected people in Enseleni community and surroundings.

In the presentation the findings are categorized thematically in order to create a holistic picture. The analysis follows similar approach. Content analysis was used on the information gathered. The findings are, therefore, presented in a summary of four categories that we decide to call themes that are further divided into sub-themes in discussions.

Themes that emerged from the research were as follows:

Theme 1. The impact of community based care centre

Theme 2. Thandukuphila as a community resource

Theme 3. Capacity Building and empowerment

Theme 4. Challenges of Community Based Care Centre

5.3 THEME 1. THE IMPACT OF COMMUNITY -BASED CARE CENTRE

The impact of the HIV/AIDS pandemic on health services, families and communities is emerging at a rapid pace. In an attempt to deal with this situation, it is now common practice for health care facilities to ration services to the communities. Much of the burden of HIV care in developing countries is now falling into households and communities (Russell & Schneider, 2000).

Most respondents acknowledged that the Centre under study has a positive and significant impact on their lives. According to Alta van Dyk (2005), Community based care, when properly organized and adequately resourced, does provide comprehensive services that include psychological, social, medical and nursing support to HIV/AIDS - infected and affected persons and their families. It many countries, especially in the developing world, it is emerging as the realistic alternative approach to cope with the crisis.

5.3.1 IMPACT TO ORPHANS AND VULNERABLE CHILDREN

There is no gain saying the fact that South Africa is currently experiencing an overwhelming HIV/AIDS pandemic. Many children are affected by HIV/AIDS as is their

parents. This situation becomes complicated when, not only families but also, those who are caregivers and other members of their communities become infected with HIV too, because of inadequate health management knowledge in respect of this condition. Hence even people, who may be helping contact the virus, become ill and might even die. The consequence of all these developments is the burgeoning number of children who are orphaned.

5.3.1.1 ORGANIZATIONAL INTERVENTION

Thandukuphila Community -Based Centre, as a community initiated organization, plays a very significant role in lives of many Orphans and Vulnerable Children (OVC) who have become beneficiaries of the program. This Centre has helped so many children who otherwise might have gone to school on an empty stomach. Hence with the assistance they have managed to continue with their education. The researcher established a clear understanding that these orphans and vulnerable children felt that Thandukuphila Centre has had a positive influence in their lives. One such respondent succinctly put it thus:

"Thandukuphila changed my life; I remember the first time when we came to this Centre with my grandmother. We had no school fees, no uniform, no stationery, but Mrs.… (Name) accepted me". The respondent continued to indicate that they were given food in the morning and at lunchtime and received school fees and even uniforms.

In addition one of the participants (OVC) who lived with his grandmother because both parents are deceased stated that the centre also played a role in character building. He said*;"they teach us to have respect, give us guidance on other things like drugs, which is difficult for my grandmother to talk about"*. Due to this pandemic most grandmothers become important part in the lives of many orphaned children. The Centre becomes pivotal as a support structure within this community of Enseleni.

The situation of vulnerable children might differ in the degree vulnerability, but their needs do not. For instance a participant (OVC) who still had both parents, but the fact is both of them are infected people, hence she was eligible to be part of this Centre. She stated that:

"It makes our life better especially my life since my mother is unemployed and the grant has stopped". She further stated that '*When my mom was sick life was difficult'*

Studies of the development, implementation and evidence-based interventions for the care of orphans and vulnerable children done in Botswana, South Africa and Zimbabwe do clearly indicate that early identification of Aids affected children is crucial; as interventions should be initiated even before their parents die (Strebel, 2004)

The majority of orphaned children, regardless of their HIV status, live in deeply impoverished households where they not only face inadequate nutrition but real starvation as well. The following statements from some of the involved children put it vividly:

"*I once decided not to come to this Centre but when I arrived at home there was no food and I felt bad, then I see that it is not helping I had to come back to this centre for meals. I realized that I couldn't survive without this centre.*"

Children who are part of the Centre's program face some challenges that disturb their lives. One of them said:

"Sometimes, it is difficult to be part of this program, sometimes you get shy because other children tease you. They say that your mother died of AIDS that is why you enter into this gate."

While these negative comments hurt, these children felt grateful they there was in any case a place they knew they could get to for basic needs as human beings. Such reliance is understood in Social Work for the positive role it plays it sustaining hope for living realistically under the circumstances they find themselves in.

He further mentioned that "*I don't think my grandmother is getting pension because she is always at home. My uncle is also not working .He only help people when they want a driver.*"

The lack of a strong social security net amid the high levels of unemployment in South Africa means that poor households and communities slip further and deeper into poverty and deprivation. Invariably the burden of coping under these difficult conditions falls on women, particularly girls and grandmothers (Dorrington, et al 2006).

5.3.1.2 COMMUNITY INTEGRATION

It is believed that the best method of care for vulnerable and orphaned children is generally found within the children's communities. Most children felt that they should be placed in the community.

"*It is better to be in the community because I am always available to my family when they need help on the other hand I can get help easily when I am staying with my family.*"

"*In your own community, your family members guide you, at the same time are able to see with whom you associate on a more regular basis. I like to stay with my friends especially…………. (Name) because she brought me here.*" Within the community, we can play and visit friends but staying in place of safety is bad because it separate you from your friends."

The Policy Framework for orphans and other children made vulnerable by HIV/AIDS (2005) outlines a broader framework for the protection and provision of comprehensive and integrated developmental services for OVC. It emphasized on mobilizing and strengthening community-based responses for the care, support and protection of orphans and other children made vulnerable by HIV and AIDS.

Dorrington, et al, (2006) emphasized that orphaned children are far better if they remain in familiar surroundings, in family units even if not with their biological families. At the same time, the pressures upon households absorbing orphaned children can be overwhelming.

Sharp and Cowie (1998) state that the early years in the life of a child lay a strong foundation for later emotional development. Many of the difficulties experienced by children later on in life can be traced back to the first relationship with primary caregivers. The family plays an important role in the upbringing and socialization of a child from an early age.

Caring for young growing children is important so that their lives are not severely harmed if their family circumstances have changed drastically and negatively. In a case study of a foster-care pilot project at Bushbuck Ridge in Limpopo province suggested that there is a

need to identify workable models to ensure that children are cared for and properly integrated into the community despite their circumstances. This could be understood as one of the reasons Enseleni community started drop-in centre for orphans and vulnerable children, as a working model.

However, one of the participants (OVC-boy) had mixed feelings that orphans should be placed in a place of safety. Despite this emphasis on the value of family environment, even approximately, some of the children expressed different views on unhappy orphans under these circumstances after visit to an institution about twenty five kilometers away. He stated;

"It is better to be in the place of safety. We once visited a place of safety in Ngwelezane and we found that all children were happy but here (at community level) everybody is labeling you. Sometimes we feel stigmatized."

In circumstances like these, the expression of views that appear to be in conflict should be seen in perspective. The comparison between community based treatment and support with institutional placement is probably based of experiences, as indicated above, that hurt the individuals concerned. Also there appears that many do not share such feelings.

The family and community-based approaches appear to best meet the child's need for security and socialization, however, they need to be supported and strengthened if they are to remain a viable way of meeting all the needs of the child (Uys and Cameron, 2003:182).

Thoburn (1994:37) also supports that the permanent placement for children in a familiar environment is important and advantageous; hence he regards it as crucial for their development.

It does become important that community- based centres develop to embrace these values for better development of these children.

5.3.1.3 CAREGIVERS'S SUPPORT
The majority of cases of orphans and vulnerable children regarded their relationship with caregivers and other people involved with them as being kind, because they take good

care of them and treat them as they would normally treat their own children. The following statement expressed that children share a good relationship with caregivers.

"Caregivers are very supportive, helpful and advising us, sometimes they give us pocket money".

"They are very good; they make us feel at home."

"They always tell us to treat each other as one family. I feel very happy when I am around Thandukuphila caregivers or staff members because they make us feel free."

The positive statements indicated in the above statements are important for the impact created through its caregivers and other people involved in the care and support of these children. It becomes significant in that these children develop strong relationships to the extent that they believe that they will have a support system even if their own biological parents die.

Caregivers is also in the position to know who supports the child psychologically and emotionally; whether the child understands what is going on in the family' and will look after the child after the death of the parent (Marston; 2003;Uys; 2003:5).

5.3.2 IMPACT TO PLWA

In the face of increasing needs of PLWHA and their families, and the inability of the formal health and welfare systems to meet these needs–particularly in sub-Saharan Africa, many countries have turned to Community Bases Care and Support. Notable program in Africa have been the AIDS Support Organizations (TASO) in Uganda, the Family AIDS Caring Trust (FACT) in Zimbabwe and the Catholic Diocese in Ndola in Zambia (Johnson's et al, 2001).

5.3.2.1 ORGANIZATIONAL SUPPORT TO PLWA

People Living with HIV/AIDS acknowledged that this organization has a positive impact in their lives.

 "This centre contributes positively to my life since I found out about my status.

"This centre really helps the Enseleni community for, e.g. there are people who are extremely poor and sick they come for food every day."

Nutrition is an important health issue for everyone, but particularly for people living with HIV/Aids. Eating healthily and maintaining your proper weight strengthen the immune system, making it better able to slow the progression of HIV to Aids and fight opportunistic diseases. Good nutrition also helps one's body tolerate medical treatments more easily and improves your sense of well being, which in turn strengthens one's immune system.

The education of community members, especially those affected appears have been enhanced by the presence of the Centre. One participant had responded that,

"Thandukuphila 2 (Satellite centre) is playing a vital role to those people who are taking treatment in that it gives them food, for lunch and supper". This balanced view; the acknowledgement of the combination between treatment and nutrition was noted by the researcher as advancement in education, especially in view of the conflicting messages to affected people in the past few years.

In social work it is known that clients and/or patients come to identify a welfare agency, a health centre and any other such place of reference when a person is in need as a saviour in one's life. This is demonstrated by the responses of the different people:

A PLWA who realized the value of assistant she obtained earlier later became a volunteer participating in the Centre's gardening and food production projects and eventually a worker (caregiver). Another one who is also worker (PLWA) is able to look after three children who were all left by their mothers as orphans. A plus point is that she believes that their mothers would not have died had they made use of a place like this Centre. Two others felt grateful that there were now in a position to share the raising and care of orphans they were looking after while they continued with their income generating activities.

The above statement is in line with the concept of social development holistic approach that promotes the well-being of the community as a whole in conjunction with a dynamic process of economic development. Many authors emphasize that there is a growing acknowledgement of the importance of the continuum of care and support services to people living with HIV/AIDS who are outside of health facilities, per se.

5.3.2.2 SUPPORT GROUPS

PLWA participants made an emphatic statement that coping with HIV/AIDS alone is a difficult experience. All participants reported that they found support group as a valuable strategy for coping, people you could rely on because they shared the same situation as yourself. The group communication, although not strictly according to group work principles was, nevertheless, a valuable experience.

"When my friend advised me to join support group, initially I ignored her because I was scared. Later I decided to follow her. I knew that I am HIV positive but I had no information about the important of checking your CD4 count, when I shared my problem with support group members, they encourage me to go for CD4 cell count. When I checked it was 50 and I was slender, huh! It was not easy, I had sleepless nights after 6 months it was 826 and now is more than that."

"When my wife was pregnant, she found that she was HIV+ and she advised me to go for test. It was not easy but I decided to go. I visited the clinic and the result were positive .I didn't check CD 4 cell count but after attending support group I understood and then I went for CD4 cell count, it was very low"

"Since I found out about my status I make sure that I attend support group. We meet every Tuesday as support group and this is very helpful."

"We started projects for PLWA like beadwork and, grass mats. Many people left our support group and joined other support groups that are better. In this support group we only get lunch and supper whereas in other support groups they get food parcels if you are taking treatment."

According to Van Dyk (2001) support group members become experts of their own lives and are empowered to help and satisfy the needs and concerns of other group members.

5.3.2.3 DISCLOSURE OF ONE'S STATUS

PLWA mentioned that they had accepted the illness and have disclosed their status, although it was also difficult for them at the beginning. They have accepted their condition through education about the disease and support group empowered them on what they should do to live longer lives.

Most PLWA feel that disclosure is very important especially to partners and close family members. Disclosure assists PLWA to accept their status and learn coping strategies.

Some clearly indicated that stress was a dangerous factor and that after disclosure and counseling it felt a load had been taken off their body, and was less shy in meeting people ordinarily.

"I think we HIV-positive people should be open about our HIV-status and educate each other."

"I wish our support group can be strong like it was before, because disclosure is helpful and relieving when you sit together with similarly affected people discussing issues that affect you alike."

They also felt that disclosing status to your loved ones is the first step to the recovery process.

"My mom was very supportive after I disclosed my status. I was very weak when I started treatment but my family was very supportive. I view my condition as all other illness and that is all I care about now".

5.3.2.4 POSITIVE THINKING AND LIVING

The researcher established a growing positive attitude among the majority of these people, that they have hope and generally accepted their HIV status. They presented themselves as people who are well informed about HIV and would be in a position to talk to others of their experiences. The following sentiments are indicative of this;

"What I learnt is that it depends on how you take this disease (HIV/AIDS) if you take it like your friend you get along very well because you know each other's weak and strong points. You need to share your problems with people that are close to you."

"I learnt that being HIV is not life sentence especially if you have accepted it, go on with the treatment regime and adopt a positive about life."

"At one stage I was very sick and I was diagnosed with diabetes but I didn't think that I would die and had hoped that I will live longer. I have not given up hope and have been infected for 10 years."

It is important to realize that even though community care had been part of the delivery mechanism for chronic and terminal care, prior to the advent of the HIV/AIDS epidemic, in the context of HIV/AIDS care, it has been linked to the inability of the health sector to absorb the large numbers of care needs related to the high prevalence of HIV (WHO, 1999).

Availability of Antiretroviral Treatment further enhanced the hopeful feeling about life. One respond stated that:

"I started treatment in 2005 and I noticed a huge difference in my life. Treatment helped me a lot because I had severe diarrhoea."

"Now there is antiretroviral treatment that helps us to decrease the viral load and increase our cd-4 counts" This showed that treatment brings hope to people living with HIV/AIDS

5.3.3   IMPACT TO CARE GIVERS/VOLUNTEERS

Heginbotham (1990) defines the concept of voluntary of this nature, as some activity or undertaking, offered in an open and generous spirit and given freely without any hint or coercion.

5.3.3.1 COMMUNITY VOLUNTEER/CAREGIVER PROGRAM

The researcher can confirm that at this community there are a fair number of people willing to be involved in volunteer work on behalf of the Centre, a significant feature in such a rural area. One such person stated, *"...someone had invited her to volunteer at the Centre as I was still unemployed. Her help would be of value. She indicated that feels obliged."*

"I can say this centre really help us as a community, without it I don't know how we could have survived. I visit our clients on a daily basis, we cook for them, feed them, bath them. I also do washing for my client. I can handle any client, sometimes family members will tell you that the client doesn't want to eat but I make sure that I feed that client and teach one family member on how to handle my client."

According to Marston (2003) local community volunteers play a very important role in community-based care programmes. Volunteers usually come from a variety of backgrounds and they may be trained and experienced professionals, trainee community caregivers, family members or compassionate community members who wish to help those in need.

Another participant (volunteer), "I had a brother who was sick and a volunteer from this centre visited him. They took care of him until he was better. During that time I had just completed matric. I felt that I also need to do the same in order to help other sick people"

Uys and Cameron (2003) assert that volunteers from within the community are more likely to visit households regularly and that the help they offer are more likely to be practical and supportive. They further mentioned that members of the community are in the best position to know which households are most severely affected and what sort of help is appropriate. They know who is dying, who has been taken of care by relatives, who is living alone and who has not enough to eat.

Therefore, volunteer caregivers are in the ideal position to identify the needs of people who are affected by the illness. The researcher ascertains that within the community-based care approach organization should make use of community members who have vested interest in the well-being of those that are infected and affected.

5.4   THEME 2: THANDUKUPHILA AS A COMMUNITY RESOURCE

Home/community- based care and support, capacitates and mobilizes communities to mitigate the effects of HIV/AIDS. The model does not imply shifting the burden to communities, but its intention is to ensure that persons who are infected and affected by HIV/AIDS have access to integrated services that address their basic needs for food, shelter, education, health care, family or alternative care and protection from abuse and maltreatment below (Froehlich, 1999)(Uys, 2003). The 2005 Policy Framework shows the bravest and most comprehensive approach that the government has adopted.

5.4.1 SERVICES RENDERED BY THANDUKUPHILA COMMUNITY -BASED CARE CENTRE

Community based services are more accessible to clients and families, decrease isolation, and provide needed interventions which can contribute to the quality of care for infected and affected people.

The respondents identified Thandukuphila as a useful centre and indicated that the organization assists them in meeting basic needs for infected and affected people of Enseleni, such as basic care for people living with HIV and AIDS, and needs for orphans and vulnerable children such as school uniform, school fees, food and other materials. The following quotes provide a summary of the view expressed by some of the respondents.

One of the committee members said, *"Thandukuphila saved many lives in this community. Sometimes I go out with volunteers for home visit .If there is a need we transport people to the hospital using the car that was donated by Lotto."*

Midgley (1995) supports that people and community have capacity to organize themselves to ensure that their basic needs are met and their problems are solved.

She further mentioned that *"We have two kitchens, one for children (they come in the morning and eat breakfast and after school for lunch, sometimes we give them supper to take it home if we don't have food parcels in that month. We also have people who are on ARVs and TB treatment; therefore, the other kitchen is for them .The organization bought lunch bags and lunch boxes for them. They get food, which is enough for lunch and supper. Most of these people are referred by clinic when it is noticed that a person is struggling to take treatment due to poverty".* These people are identified by community volunteers and caregivers during home visit.

One other volunteer said *"I feel that OVC are the main beneficiaries of the programme it makes their life better It takes them off the streets. Gives them food, school uniform, medication (day care centre children). It also educates them about teenage pregnancies, drug abuse sexual education and HIV/AIDS".*

Committee member support the idea that *"Caregivers/Volunteers are playing a great role in this centre. They do home visits to clients, train the primary caregivers on how*

to care, bath and feed the sick person. They do workshops with neighbors an opportunistic infections and how to prevent them. They also distribute condoms and pamphlets".

Williams, & Campbell, (1998) as quoted by Russell &Schneider, (2000) found that South Africa has one of the most rapidly growing HIV epidemics in the world. In South Africa a number of organizations have emerged to provide Community–Home Based Care (CHBC) as a community response. It was noted that the government response has not been adequate due to increasing number of infected and affected people.

The researcher also ascertained that although this Centre is trying very hard to address HIV/AIDS issues, but poverty as a consequence of HIV infection could see the poor adopting various mitigation strategies to cope with disease that usually exposes them to more complex problems in relation to their infection. Poverty increases people's vulnerability to HIV/AIDS by increasing their likely exposure to unsafe sexual practices

The committee member confirms that although they are trying to assist the community, but owing to poverty people expose themselves to unsafe conditions. The following statement illustrates the above:

"Poverty is a serious problem in this community; youth must know that you must work hard in order to survive".

"It is not easy, but I don't want to lose hope, but when you listen to statistics in KZN as a highest, you feel disappointed. I fell that poverty plays a great role especially in rural areas."

"We have income generating project to curb poverty. There is a big vegetable garden that was donated by Inkosi (Tribal authority). We use those vegetables to cook for OVC and PLWA but it is not enough".

Cohen (1998) argues that it is not surprising that poor adopt behaviors that expose them to HIV infection due to poverty.

Some people would create complex problems for themselves also and blame the government for that. A person on TB/ARV treatment had decided to stop getting it because his grant would stop as he was diagnosed to be improving. Such dependency is a

problem. Poverty is also observed to be aggravating the physical as well as the mental well-being of people living with HIV/AIDS.

5.4.2 COMMUNITY PARTICIPATION AND COMMUNITY SUPPORT

Community- Based Care Centres cannot be successful if they do not get support and participation from the government, NGOs, and community stakeholders. Russell& Schneider (2000) state that in some instances there have been efforts to develop alternative community based care structures; through programs such as home based care and hospices. Parallel to these initiatives, the growing number of AIDS orphans is causing some communities, community –based organizations (CBO) and non – governmental organizations (NGOs) to identify feasible strategies to protect and provide for the basic needs of this extremely vulnerable group.

Presently the focus now is on how to achieve greater community participation in meeting the needs of people who are infected and affected by HIV/AIDS.

5.4.3 POSITIVE COMMUNITY RESPONSES

Most respondents reported positive experiences with regard to community support and participation, while others reported that local people are supporting them but this is not enough compared to people, who are not from Enseleni. The locals, as such, did not appear to have much of the support resources adequate enough to run such a programme meaningfully.

One of the respondents reported a very heartening incident in support that despite meager resources some community members went out of their way to be helpful, for instance:

"The Principal from the local school donated R10 000 last month to the Centre." before the researcher was there.

There was a further indication that some local churches were accepting of People Living with HIV/AIDS and insisting that they be treated like anybody else; their status did not mean they should be isolated. These also participated in projects or structures to educate the community about HIV/AIDS. An example cited by one volunteer is quorted here as saying:

The local Catholic Church is helping us a lot in this Centre in terms of some our needs. They even built a two-bedroom house for me because I was walking up and down everyday doing community awareness and educating community about positive living since I am living with this virus for 9 years without treatment.''

Uys (2003) supports that family and community involvement in the care of their own members create general Aids awareness in the community and this helps to break down fear, ignorance, prejudice and negative attitudes towards people with AIDS.

Other forms of assistance had come from industry people as far away as from Richards Bay, some twenty odd kilometres away and also from Pietermaritzburg, two hundred and fifty kilometers away.

"Hillside, an Aluminum Smelter at Richards Bay renovated our Thandukuphila 2(Satellite) kitchen"

"Our poultry project was sponsored by the big poultry company at Pietermaritzburg."

In addition the centre receives support both from a government office and some a non-governmental organization and from private people, for example Department of Health is also supporting them.

The department of Health is supplying us with enough food for children in day care centre and medication including ARV and primary health care medication. It also assists us with home-based care program. Recently they introduced outreach program; we visit each and every household and complete forms. These forms give us more information on how many people in that house, how many employed and schooling and those that are not employed nor schooling we asked them why and that is how we get sick people and identify vulnerable children".

Lewis and Lewis (1989) support that community members could identify vulnerable groups or individuals or individuals in their particular settings and develop programs that provide both support and strengthen problem-solving skills.

"We work hand in hand with local clinic because they supply us with list of people who are taking treatment on monthly basis, and then our volunteers visit them for assessment if there is a need for our intervention''

These organizations had to invest time in maintaining the governmental relationships as a key element to the programs success. Even, now the major problem that most CHBC programs face is establishing and maintaining functional links and relationships with government structures and other related agencies (O'Neill and Higginson, 2003).

Few negative perceptions were also reported that shows that there are still some elements in the community that discriminate and stigmatize affected people. The researcher felt very encouraged when most of participants indicated that they were not discouraged by the negative and discriminatory remarks of the some community members.

5.4.4 INVOLVEMENT AND MOTIVATION

The length of participation of some of the staff and volunteers clearly indicated their motivation to promote the work of the Centre. One participant related how his wife passed away in 2003, after being diagnosed with HIV prior to the introduction of treatment. In 2004 he decided to be part of the Centre. Since then he has not changed his mind. Another, a retired nursing sister, also decided to make use of her knowledge and expertise since 2006 and had been involved in promoting projects in this community and other neighboring ones. She felt good of what she was contributing.

Thus the views expressed by Uys and Cameron (2003) that there is general consensus that interventions to assist HIV/AIDS infected and affected people should be based in and owned by the affected community themselves as well other who show motivation and commitment. More involvement by the community members should, therefore, be encouraged.

5.5   THEME 3. CAPACITY BUILDING AND EMPOWERMENT

According to White paper for Social Welfare (1997), capacity building refers to the development of skills for the promotion and building of organizations. There are different levels of capacity building namely: upgrading of skills, reviewing and improving methods used to promote organization development. It also refers to the development of a learning organization capable of a continuous self development process. Generally, it is used to refer to skills development in a wide range of areas such as specialist knowledge

and skills, popular education and training for example life skills and social competence promotion.

5.5.1 ORGANIZATIONAL AND INDIVIDUAL CAPACITY BUILDING

A number of other non-government as well as community organizations are involved in training community development workers and community volunteers to assist families with community- home care (Uys, 2002).

The participants viewed empowerment and capacity building of people as an integral part of community based care. The participants mentioned the income-based programs. Skills training as ways in which this could be realized. This can be done on an individual basis or as well as on a larger scale. Many participants appreciated training that they get from this centre. The following responses indicate that they view empowerment and capacity building as part of community based care.

"Different organizations provide training in this centre –child minders, kids club (train kids on painting and to make Christmas cards. People are also trained on Home based Care and DOT support.

"They teach us about HIV/AIDS, teenage pregnancy and other stuff. Love life and Usibindi programmes (NACCW) are also helping us. Usibindi also help us with home works and teach us life skills during school holidays.

"There is an after school care program that focus mainly on Orphans and Other Vulnerable children for life skills development. They do different activities like beadwork, craft, cards, and painting. During the school holiday children attend Youth holiday Program that teach them about life skills, and life orientation program. The children are also involved in gardening project"

"There is another organization from Cape Town called Aids Foundation South Africa (AFSA) that trained our committee on project management. They were very good."

AFSA is committed to support Community Based Organizations to limit the spread of HIV infection and mitigate the impact of the epidemic in the most vulnerable communities of South Africa. It supports several community initiatives that address the needs of orphaned and vulnerable children and their caregivers.

"I have attended Home Based Care training, HIV/AIDS counseling course, Computer, Debriefing'' She further mentioned that*" Debriefing is done every 3 months and assists us to deal with stress. Debriefing is very important because sometimes it is difficult to deal with loss because some of our clients died whilst you are busy trying to help''.*

"Training helps me because now I know that if the person has TB what to do. I would also like to get training on counseling. Sometimes one visits a person and one feels that he or she needs counseling and indeed the whole family". In social work we always take into account that an individual is not an isolated entity, family counseling also will assist provide a strong supportive base once they are in a 'correct' mode

Some of the participants were of the opinion that more training should take place. Their responses with regard to training needs can be summed up as follows:

Some people still need to be trained on counseling because they are struggling to deal with difficult clients. Counseling is important for e.g. I had a client who was on TB treatment more than three times, but not recovering, as it should have happened. I counseled him on importance of knowing one's health status. He agreed to be escorted to the clinic where they took over with the process. Since then he is on ARVs and he is doing well. The counseling skill and literary holding him by the hand, as it is said, helped to change him altogether.

Some caregivers have other counseling experiences that help them in caring for PLWHA (home based care)

"I attended computer course, privately, because I wanted to be computer literate. Counseling and Home Based Care was done by Indlelayempilo Organization through Africa Centre. This training helped me a lot .It really empowered me but other people, do not have these kind of trainings"

One of the caregivers/volunteers state as already indicated that*, "We also attend debriefing every three months which is done by organizations called Indlelayempilo."*

Uys and Cameron (2003) support the involvement of caregivers in capacity building, stating that they should be given further training in order to be effective in their diverse

roles, including those related to identifying and supporting HIV orphans and affected children and their families.

5.5.2 EMPOWERMENT

Heginbotham (1990:51) regards empowerment as part of community care, which implies revaluing and empowering people to assist society to change in a way to lessen any future tendency to devalue.

One committee member stated that, *"Thandukuphila, as a part of its programs, creates awareness on the rights of children using the Children's Charter and that the community at large are educated and empowered by Thandukuphila on how to identify signs and symptoms of abuse .It also creates awareness on positive living"*

One other participant, who is a volunteer, stated*; "This centre identifies HIV/AIDS orphans and PLWA who could be part of program through schools, community members and the local council and traditional leader"*

An Induna is part of Thandukuphila committee and he helps us a lot to identify needy families .The organization also involves community through forums. He also informs people about our centre services that are available during their Imbizo at Chief's place"

The following statements illustrate that empowerment is taking place in this Centre:

"This centre exposed people in different trainings in order to empower them like Pre and post test counselling, home based care, awareness campaigns, education and training on home based care and caring for OVC, skills training and development program e.g. sewing, gardening, fundraising skills"

"I am feeling good about what I am doing. I visit some of my clients almost everyday. It doesn't affect me instead it empowers me that I am contributing positively to the lives of other people. I feel great when I see the person walking again"

"This Centre helps us a lot .I believe that once one is enlightened and empowered one needs to be independent .One needs to give other people chance who are still in need. There are many things that community is gaining in this Centre other than food you gain knowledge and skills"

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"I feel that HIV courses assist people to perform their duties effectively"

"I think HIV positive people need support and to learn to be independent. Some of us need to learn and appreciate what it means to give other people a chance. Presently I am working as security in this centre, that means I am empowered and I don't need food parcels. But other people keep on coming back all the time.

"Every Thursday we meet and share our experiences as a group of caregivers and volunteers. These meetings empower us on how to deal with problems, for example; I had a client who stopped ARV treatment and decided to take traditionally medicine. My buddies helped me on how to deal with him"

5.6 THEME 4. CHALLENGES OF COMMUNITY -BASED CARE CENTRE

5.6.1 CHALLENGES FACING THANDUKUPHILA

First and foremost the researcher clarifies that the organization operates in a tribal semi-rural area. Such areas have been bypassed by infrastructural development, socio-economical development experienced by counterparts in urban and metropolitan areas. Of significance is that these areas have very little economic base of their own. Also they are mainly dormitory areas, of course, with a strong cultural base.

Hence Thandukuphila as an organization operates with some limitations. The respondents acknowledged that Thandukuphila centre is very helpful, but that is has some challenges as one respondents commented:

"The centre is good, but it is difficult to see it getting stronger and offering more that basic services. When one thinks of these children (OVC and sick people one becomes scared that what would happen should this program be forced to curtail its work program. This would mean they are going to die, it is difficult"

The respondents' opinions were that if these challenges could be addressed, it would even make a larger impact in the lives of infected and affected people. Respondents indicated the following challenges:

"The criteria for selecting beneficiaries should be reviewed"

"Improve quality of food especially school going children, it should be proper diet with at least one fruit a day."

"Both Thandukuphila kitchens must operate 7 days a week because if they operate 5 days what about weekend, people still need food over the weekend in order to take treatment"

"There is a need for full time social worker as we use to have it before because it is difficult for us to report welfare cases to clinic social worker. One of respondents who are a caregiver indicated that the social worker comes once a week on Tuesday and we only come to the centre on Thursday, therefore we cannot report our cases."

"When you visit the family you find that the person is sick and nobody is working in that family, no money for transport. Things like that frustrate you. The other helping organizations are far away" This pointed to a problem of a lack of a structured network programming that would assist in utilizing even the available resources more economically."

"We need our social worker at Thandukuphila in order to report social problems as caregivers because presently the social worker comes one a week and we don't even see her at all because we come once at the centre only on Thursday"

"I still feel that we need a full time social worker because there are people who are sick need and need social development intervention. Sometimes you refer a person to the clinic social worker and they don't get help. Because queue is always long as a result they do not get help."

"The centre can assist HIV+ people to exercise .If we can participate in different sports activities like playing soccer, fun walk. We don't want people to feel sorry for us I wish to see myself running or playing football."

"People who are on ARVs because they get food from Monday to Friday then on weekend they don't get food on Saturday and Sunday. This treatment can make you hungry."

"PLWA must get more help and support, look at me I have recovered so quickly because my mother is a nurse. She gives me lot of support. I was a slender and now I am overweight."

"The rate of OVC is rapidly increasing, yet this centre does not have enough resources to provide for all services to needy children."

"The number of people within the community that need soup kitchen is also increasing yet the resources are not enough."

"We need food parcels for our clients, sometimes family members get frustrated when you come with a pen and the paper and say "you just came to see us suffering and write that'. They are expecting you to come with food parcel and grant. At the moment we don't have food parcels, we only give them porridge."

"The number of infants who are HIV positive is also increasing and most of them are taking treatment (ART) we don't have enough resources to assist them to get to Ngwelezane Hospital for the treatment as the Nseleni clinic does not provide ARV treatment for children under the age of 14 years."

5.7   CONCLUSION

In the presentation, analysis and interpretation of data has been attempted to create a clear picture of the organization Thandukuphila Community –Based Care Centre. As indicate, despite its many challenges the organization meets great challenges that would otherwise be left unattended and people suffering untold misery and death indeed. The National Guidelines on Home-Based Care that paved the way for the development of such centres by enterprising and/or motivated people together with the Policy Framework on Orphans and Vulnerable Children are very instruments at official level. However, implementation should be improved in helping those communities that try to develop services. Municipalities and local authorities are supposed to play a role in such development, but some areas have yet see to experience any meaningful development, In the meantime the needs of infected and affected people as well as those who become vulnerable keep on rising. The big challenge has to be faced squarely.

CHAPTER SIX

6. CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

In this final chapter the researcher presents the summary of the major findings of the study discussed in previous chapters. The chapter further explores the study's limitations and offers recommendations for future research.

6.2 SUMMARY OF THE KEY FINDINGS

The main purpose of the study was to assess the impact of Thandukuphila Community-Based Care Centre on the lives of HIV/AIDS infected and affected people (beneficiaries) and to explore the experiences of beneficiaries of the programme. It has been argued throughout the investigation that much of the burden of HIV/AIDS pandemic is now falling into the hands of families and communities.

The findings indicated that Thandukuphila Community- Based Care Centre has a positive and significant impact on the lives of HIV/AIDS infected and affected people who are beneficiaries of the program. The respondents identified Thandukuphila as a useful centre and indicated that the organization assists them in meeting basic needs for infected and affected people of Enseleni, such as basic care for people living with HIV and Aids, and needs for orphans and vulnerable children such as school uniform, school fees, food during the day and other materials they may be in need of.

The results showed that Thandukuphila, as a community initiated organization, plays a very significant role in lives of many Orphans and Vulnerable Children (OCV) who have become beneficiaries of the program. This Centre has helped so many children who otherwise might have gone to school on an empty stomach. Hence with the assistance they have managed to continue with their education. The researcher established a clear understanding that these orphans and vulnerable children felt that Thandukuphila Centre has had a positive influence in their lives.

Most respondents felt that OVC are the main beneficiaries of the program, it makes their life better it takes them off the streets gives them food, school uniform, medication (day

care centre children). It also educates them about life skills like teenage pregnancies, drug abuse sexual education and HIV/AIDS. Many authors support that Orphans and Vulnerable Children are better to be cared within your community. They need to group in a positive, safe and caring environment. People Living with HIV/AIDS in this study also confirmed the argument that it is better to be cared in one's own community than in hospitals or hospices. PLWA also found support group that they attend in this community centre as a valuable strategy for coping with this pandemic. Most PLWA feel that disclosure is very important especially to partners and close family members. Some clearly indicated that stress was a dangerous factor and that after disclosure and counseling it felt a load had been taken off their body and mind, and was less shy in meeting people ordinarily.

They also felt that disclosing their statuses to their loved ones is the first step to the recovery process. They have accepted their condition through education about the disease and support group empowered them on what they should do to live longer lives. It was found that the most PLWA are well informed about HIV/AIDS and its progression. It was noted that this helped them to cope much better with opportunistic infection. Van Dyk (2001) contends that group members become experts of their own lives and are empowered to help and satisfy the needs and concerns of other group members.

The results of the study also indicated that caregivers play an important role in the care of Orphans and Vulnerable children. It became significant in that these children develop strong relationships to the extent that they believe that they will have a support system within the community, even if their own biological parents die. Furthermore, the results showed that community volunteers play a great role to the success of this centre. All volunteers were from within the community and the visit households for infected people regularly and they know their community. Uys and Cameron (2003) support that members of the community are in the best position to know which households are most severely affected and what sort of help is appropriate. They know who is dying, who has been cared by relatives, who is living alone and who has not enough to eat. Result of this study concurs with Marston's (2003) view that local community volunteers play a very important role in community-based care programs. Volunteers usually come from a variety of backgrounds and they may be trained and experienced professionals, trainee

community caregivers, family members or compassionate community members who wish to help those in need. The finding highlights that both Day Care Centre and school going children (OVC) are the main beneficiaries of the program, it makes their life better it takes them off the streets gives them food, school uniform, medication (day care centre children). It also educates them about life skills like teenage pregnancies, drug abuse sexual education and HIV/AIDS, which lays the basic foundation of life.

In addition to this, results also indicated that caregivers play an important role in the care of Orphans and Vulnerable children. It became significant in that these children develop strong relationships to the extent that they believe that they will have a support system within the community even if their own biological parents die. Most respondents shared positive experiences with regard to community support and participation, while others reported that local people are supporting them but it is not enough compared to people who are not from Enseleni. The locals, as such, did not appear to have much of the support resources adequate enough to run such a program meaningfully. In addition the centre receives support both from a government departments and some Non-governmental organization and from private people, for example Department of Health and Department of Social Development fund most of their services.

Above all results also showed that community stakeholders both local and outside have made positive impact to their lives. They promote the sense of partnership. Participants mentioned different individual and other organizations like churches, CBO, s are very supportive to people who are infected and affected people. Many authors support that CHBC programs cannot be successful, unless they receive active support and participation from the Government, NGOs, and significant amount of community initiatives.

The department of Health was found plays a significant role to the success of the program especially to the day care centre children and home based care program. It is supplied them with enough food for children in day care centre and medication including ARV and primary health care medication. It also assists us with equipment of home-based care program like nutritional food parcels, stationery, gloves, porridge, nappies, etc. However, it was established that the insufficient ongoing home-based care resources and equipment

as stipulated in Home based care guidelines has hindered the effective services rendered to PLWA.

The community outreach program that has been introduced by Department of Health was also found as the best vehicle to minimize HIV /AIDS burden and poverty in households. Volunteers visit each and every household and complete need assessment forms. These forms give them information on how many people in that house, how many employed or still at school and those that are neither employed nor schooling. It also sought to establish why and how they get sick people and identify vulnerable children. This programme was found as a good initiative to combat HIV/AIDS in the community.

Community members could identify vulnerable groups or individuals or individuals in their particular settings and develop programs that provide both support and strengthen problem-solving skills. They further emphasize that a number of community-based programs have begun to demonstrate the tremendous potential of outreach programs to vulnerable clients (Lewis and Lewis, 1989). Few negative perceptions were also reported by OVC and PLWA that show that there are still some elements in the community that discriminate and stigmatize beneficiaries of the program. However, the researcher felt very encouraged when most of participants indicated that they were not discouraged by the negative and discriminatory remarks of the some community members.

The researcher established that there is a link between the length of participation in the program and some of the staff and volunteer's involvement clearly indicates their motivation to promote the work of the Centre. Caregivers /Volunteer's motivation to continue with care giving is entrenched in their love for the community. However, caregivers and other volunteers expressed the need for support to help them to continue with care giving. They need to be equipped with proper skills and training and to be supported through ongoing counseling and debriefing. Most of the participants were of the opinion that more training should take place. However, they appreciated training that they get from this centre and they view empowerment and capacity building as part of CHBC. McWhirter et al (1993) explained that empowerment helps counselors and families to actively confront their environment rather than passively accept their conditions as unalterable.

Results also showed that the majority of orphaned children, regardless of their HIV status, and PLWA live in deeply impoverished households, where they not only face inadequate nutrition, but starvation as well. The researcher also ascertained that although this Centre is trying very hard to address HIV/AIDS issues, but poverty as a consequence of HIV infection could see the poor adopting various mitigation strategies to cope with disease that usually expose them to more complex problems in relation to their infection. Poverty increases people's vulnerability to HIV/AIDS by increasing their likely exposure to unsafe sexual practices. Dependency and apathy were also found as a serious problem amongst the PLWA. Some people would create a complex problem for themselves also and blame the Government for that. A person on TB/ARV treatment had decided to stop getting it because his grant would stop as he was diagnosed to be improving.

6.3   RECOMMENDATIONS

Community Based Care Programs should have an integrated approach and not just focus on one aspect. Community- Based Care Programs should reflect a comprehensive developmental approach, which is based on the concept of social development.

A developmental approach encourages income generating activities, sustainable development, community participation and the creation of an enabling environment for community participation and involvement.

This participation should include community stakeholders such as churches, Government sectors, private sectors, community organizations and other NG0'S. Community stakeholders should be involved at a planning phase of the program of the ownership of the encouraged. In order to promote partnership CHBC must establish forums where all role players can discuss coordinated plans and problems related to service delivery. There should be forums that assist identifying HIV/AIDS orphans and devastated people with the help of community members and different structures within the community. Community members should be involved for better understanding of the roles and responsibilities of a caregivers/volunteer. This support the aim of Social Welfare Policy which is to build self–reliant community that is equitable, sustainable, accessible, people centred and developmental (White Paper for Social Welfare, 1997).

The community- based care should focus more on income generating activities and Department of Social Development must monitor these activities for effective community development program. This may assist to alleviate poverty on infected and affected people. Social Welfare policies and programs should be targeted at poverty prevention alleviation and reduction and should focus on capacity building and empowerment.

The researcher established that although this Centre receives help from government, but government officials are doing little to monitor and evaluate service rendered to ensure effective service delivery. Department of Social Development should implement and design Monitoring and evaluation mechanism for Community Based Care for HIV/AIDS infected and affected people. The government ought to ensure that CHBC should have a clear organizational strategic planning. According to Goodstein, Nolan and Pfeiffer (1992:1) strategic planning is the process is the by which guiding members of an organization (CHBC), envision its future and develop the necessary procedures and operations to achieve that future. The government should shift from focusing on problem (HIV/AIDS) and concentrate on strengths in order to empower people. The focus should be on strength-based approach which is based on the concept such as empowerment, partnership, facilitation and participation. This concerns itself with moving away from problem-based approach to one that is solution -focused. The program should address the gap in skills development in areas like HIV/AIDS counseling, terminal care and home based care through a formal and informal training process. Educational programs should be conducted continuously as well as assessed for its efficiency. The recruitment and maintenance of volunteers should be an ongoing program.

The department of Social Development must provide this centre with full time social worker for effective service delivery and this would be easy for devastated people to get help. Regular debriefing sessions and should be conducted professionals social workers and psychologists. Social workers should be available an anytime should caregivers /volunteers need counseling. Trauma counseling following the death of clients should also be provided to caregivers and volunteers. The government ought to provide sufficient financial budget to Community -Based Care Centre, train committee members on financial management and management of organization, because if people are not

train they would not be able to utilize funds accordingly. The program should be regular supervised by a professional people like social workers and health care worker.

Factors related to the sustainability of the CHBC should be explored. There should be proper HIV/AIDS awareness at community level to educated infected and affected families about this pandemic. Thandukuphila should work hand in hand with Social Development and Department of Health to promote HIV/AIDS awareness within the community to avoid stigmatization of beneficiaries of the program. The program should be supported and strengthened in order to be sustainable. According to White Paper of Social Welfare (1997), it is important that there must be a balance between preventative, rehabilitation and developmental program to ensure sustainability.

6.4   RECOMMENDATION FOR FUTURE RESEARCH

On the basis of the findings of this study the researcher wishes to recommend that:

Further research should be done focusing on type and quality of assistance needed by the community based initiatives especially in the rural areas. There is need to devise appropriate monitoring and evaluating criteria to assist in the standard of services rendered to HIV/AIDS infected and affected people by these Communities -Based Care Centres.

6.5   CONCLUSION

In South Africa individual, families and communities have been severely affected by HIV/AIDS especially in KwaZulu-Natal. The research exercise itself was a privilege in that it was informative in many respects, especially in the enormous challenges faced at field level.

 Most importantly, however, is that the government has it as policy to involve communities to be partners in the fight against the HIV/AIDS pandemic, but there is inadequate assistance from government to some of the communities that have started these initiatives especially those in the rural areas. The efforts of the ordinary citizens should be supplemented at concrete level so that their enthusiasm should not dissipate in this important area. It, therefore, becomes clear to the researcher that there is need for a promotional work to be done at community levels, so that these community- based

initiatives are strengthened to be effective as partners in the fight against the pandemic of HIV/AIDS.

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ANNEXURE 1

PROJECT COORDINATOR/COMMITTEE MEMBERS

BIOGRAPHICAL INFORMATION

GENDER	**MALE**	☐
	FEMALE	☐
MARITAL STATUS	**SINGLE**	☐
	MARRIED	☐
OCCUPATION	**COMMITTEE MEMBER**	☐
	PROJECT COORDINATOR	☐
	CHAIRPERSON	☐
	OTHER	☐
LENGTH OF SERVICE-THANDUKUPHILA	**0-2years**	☐
	2-5years	☐
	5-10years	☐
	10 +years	☐

➢ **How did you get involved with Thandukuphila and what motivated you?**

➢ **How long Thandukuphila Community Based Care Centre has been operating?**

➢ **How long have you been in charge/member of committee?**

➢ **What is your role in terms of functioning of the program?**

➢ **What does Thandukuphila Community Based Care Centre entails?**

➢ **How does Thandukuphila address HIV/AIDS issues?**

➢ **Do you have any selection criteria in terms of choosing beneficiaries of the program?**

➢ **Who do you think are the main beneficiaries of Thandukuphila Community Based Care Programme? How do they benefit?**

➢ **What difference Thandukuphila is making in the lives of OVC and PLWA and Enseleni Community?**

➢ **Do beneficiaries receive any skills training? What kind of skills is offered?**

➢ **What do you feel are the strengths of Thandukuphila Community Based Care Programe?**

➢ **What do you feel are the challenges and what areas do you feel could be improved?**

➢ **Give an indication of the support by the local community?**

➢ **What other support /sponsorship do you get for the benefit of the centre?**

ANNEXURE 2

ORPHANS AND VULNERABLE CHILDREN

BIOGRAPHICAL INFORMATION

GENDER	**MALE** ☐	
	FEMALE ☐	
AGE	**13-15** ☐	
	16-18 ☐	
	18+ ☐	
GRADE	**1-4** ☐	
	5-7 ☐	
	8-10 ☐	
	11-12 ☐	
	OTHER ☐	
LENGTH OF INVOLVEMENT	**1-2years** ☐	
	2-5years ☐	
	5-10years ☐	
	10 +years ☐	

➢ **Why did you become attached to the Thandukuphila?**

➢ **What benefit have you achieved /received?**

➢ **How would you describe your relationship with the caregivers and Thandukuphila staff members?**

➢ **How do you compare your life with other children who are not part of Thandukuphila?**

➢ **How helpful are people in the community e.g. Councillors, Induna, Educators?**

➢ **In your view, how would children without parents be taken care of?**

➢ **What do you feel about placing children in children's home as opposed to leaving them in their own community?**

ANNEXURE 3

CARE GIVERS/VOLUNTEERS

BIOGRAPHICAL INFORMATION

GENDER	**MALE**	☐
	FEMALE	☐
MARITAL STATUS	**SINGLE**	☐
	MARRIED	☐
OCCUPATION	**CAREGIVER**	☐
	VOLUNTEER	☐
LENGTH OF SERVICE-THANDUKUPHILA	**1-2years**	☐
	2-5years	☐
	5-10years	☐
	10 +years	☐

➢ **What motivated you to become a caregiver/volunteer?**

➢ **What are demands upon you as a caregiver/volunteer?**

➢ **Did you receive any training when you started as a caregiver? What you were trained on?**

➢ **Who provided you with the training and what did the training involve?**

➢ **Having been trained how do you feel capable in delivering Community Home Based Care services?**

➢ **What recommendations would you make for future training?**

➢ **Who are the main beneficiaries of the services you provide?**

➢ **What services do you offer?**

➢ **Do you receive any support? (Economical support-stipends/ remuneration, transport, protective clothing, quipment.Social support/Emotional support in terms counseling /debriefing, Support groups.**

➢ **Who offered support?**

➢ **What is the community response towards services you offer?**

➢ **Impact of caring in your life**

➢ **What do you need to continue doing care giving?**

➢ **Do you ever take leave, if so how often?**

➢ **Do you receive any other benefits for your work in Thandukuphila?**

ANNEXURE 4

PEOPLE LIVING WITH HIV/AIDS (PLWA)

BIOGRAPHICAL INFORMATION

GENDER	**MALE**	☐
	FEMALE	☐
MARITAL STATUS	**SINGLE**	☐
	MARRIED	☐
LENGTH OF INVOLVEMENT	**1-2years**	☐
	2-5years	☐
	5-10years	☐
	10 +years	☐

- ➢ **Why did you become attached to the Thandukuphila?**

- ➢ **What benefits have you achieved /received?**

- ➢ **What is your view about HIV/AIDS Community Based Care Centres?**

- ➢ **How do they help the community to deal with HIV/AIDS?**

- ➢ **What are some positive things in your community that are supporting people who are infected and affected by HIV/AIDS.?**

- ➢ **What role does the community play in the program daily activities?**

- ➢ **How do you evaluate the benefit for individual person?**

- ➢ **How do you evaluate the benefits of the community?**

- ➢ **Any suggestions that would strengthen the delivery of Community Based Care Services in Thandukuphila?**

- ➢ **How has Thandukuphila impacted on the beneficiaries and the community?**

- ➢ **What are some of negative things in your community that are against people who are infected and affected by HIV/AIDS?**

- ➢ **What would you recommend in general to improve the delivery of Thandukuphila community based care services?**

ANNEXURE 5

Dr N H NTOMBELA
Head of Department (ACTING)
Social Work

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ntombela@pan.uzulu.ac.za

DATE:14 October 2009

TO WHOM IT MAY CONCERN

<u>TO:THE IMPACT OF THANDUKUPHILA COMMUNITY BASED CARE CENTRE TO BENEFICIARIES</u>

This is to confirm that Ms Zamakhosi Mchunu (student number 035149) is a registered MA (Social Work) candidate with the University of Zululand (UNIZUL).
As part of the requirements for the Master's degree ,she has to undertake research activities to complete a dissertation of a limited scope .Her proposal has served with the Ethics Committee of the Department of Social Work at UNIZUL and has been approved.

This letter serves to request that Thandukuphila Committee (Chair person) gives Ms Mchunu access to conduct research in the Institution and obtain information for the purpose of the research exercise. Ms Mchunu would like to commence research activity on the 19th October 2009.

While undertaking the research, Ms Mchunu will remain accountable to her Supervisor as well as Co-Supervisor, Dr N Ntombela and Professor S V.Nzimande respectively. In this regard, she is bound by the policies of ethical research conduct as set by University of Zululand. We have no doubt that .Ms Mchunu will act appropriately , responsibly and professionally at all times .She will ensure that all information regarding your services or furnished by staff and clients remain secure and strictly confidential at all times. No names of the clients will be cited in the research project.

Thanking you in anticipation of your response.

Yours Sincerely

N H Ntombela

Dr N H Ntombela
HEAD OF DEPARTMENT(ACTING)
SOCIAL WORK

Dr N H NTOMBELA
Head of Department (ACTING)
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DATE:16 October 2009

TO WHOM IT MAY CONCERN

On behalf of Dr N.H.Ntombela a (ACTING HEAD OF DEPARTMENT) and Prof S.V.Nzimande (CO-SUPERVISOR) of the Department of Social Work in University of Zululand, I hereby request you to take part in the research project entitled "The impact of Thandukuphila Community Based Care Centre to beneficiaries".

Your participation in this study is entirely voluntary. You may choose not to participate without any consequences to you. Should you choose to participate and later wish to withdraw from the study, you may discontinue your participation at any time.

Research: Zama Mchunu
Cell: 083 751 3473
E-mail:zmcunu@quala.co.za

Co-Supervisor or Prof S.V.Nzimande
Cell: 083 774 2338
E-mail: businfo@alberts.co.za

If you wish to participate in this study, you should sign below.

Date --------------------------- Signature for consent -----------------------------

Thanking you for participation.

---Researcher (ZAMA MCHUNU)