Models of care for antiretroviral treatment delivery:

A faith-based organization's response

Marisa Wilke

MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY: A FAITH-BASED ORGANIZATION'S RESPONSE.

by

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DECLARATION

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------------------------------------ 14 April 2012

Marisa Wilke

Letter from promoter

Letter from editor

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CONTENTS

LIST OF ACRONYMS

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal Care
ART	Antiretroviral treatment (highly active antiretroviral therapy)
BMI	Body mass index
Br	Brother (refers to a male Religious)
CATHCA	Catholic Healthcare Association
CHSR&D	Centre for Health Systems Research and Development
CRS	Catholic Relief Services
DoH	Department of Health
DNA	Deoxyribonucleic acid
EDM	Electronic drug monitoring
FBO	Faith-based organization
Fr	Father (referring to a Religious father/priest)
HBC	Home-based care
HCT	HIV counseling and testing
HCW	Healthcare worker
HIV	Human immunodeficiency virus

INH	Isoniazid
IPU	In-patient unit (Hospice)
KZN	kwaZulu-Natal
LTBI	Latent tuberculosis infection
MOC	Models of care
NGO	Non-governmental Organization
NGT	Nominal Group Technique
NHLS	National Health Laboratory Service
NIM-ART	Nurse-initiated and managed ART
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTIs	Nucleoside reverse transcriptase inhibitors
NSP	National Strategic Plan
NtRTI	Nucleotide reverse transcriptase inhibitor
OIs	Opportunistic infections
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary healthcare
PI	Protease Inhibitor
PLWHA	People living with HIV & AIDS

PMTCT	Prevention of mother-to-child transmission
PN	Peripheral Neuropathy
PTB	Pulmonary Tuberculosis (*Mycobacterium tuberculosis*)
QOL	Quality of life
RN	Registered nurse
RNA	Ribonucleic acid
SACBC	Southern African Catholic Bishops’ Conference
SAG	South African Government
SANC	South African Nursing Council
Sr	Sister
SSA	Sub-Saharan Africa
STIs	Sexually transmitted infections
TB	Tuberculosis (*Mycobacterium tuberculosis*)
UFS	University of the Free State
UNAIDS	United Nations Program on HIV/AIDS
USA	United States of America
USG	United States Government
USAID	United States Agency for International Development

VL	Viral load
VZV	Varicella-zoster virus

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The researcher has obtained signed consent forms for all the photos of patients used in this document. Consent forms were not included in the document as it would identify the patients, copies are available on request.

PART I

Part I of this document will provide a historical background to Catholic healthcare in South Africa before the methodology will be discussed in Chapters Two and Three, forming a basis to understand the conducted study. The role the Catholic Church played in healthcare (more specifically within South Africa) is discussed to contextulize the study. It is not within the scope of this study to describe the complete historical development of all faith-based organisations over the world and the role they played in healthcare.

CHAPTER 1: HISTORICAL BACKGROUND

Christianity has played a major role in the care of the sick (Donahue, 1985: 101; Mellish, 1985: 26). This chapter will focus on the role the Catholic Church played in the development of nursing, and highlight some of the groundbreaking work that was done by the Religious Orders (monks and nuns), and the vital role that they played in establishing medical services and nurses' training in South Africa. In similar fashion the Catholic Church is still playing a vital role in the care, support and treatment of the human immunodeficiency virus (HIV) infected and HIV-affected today. The role of the Church's involvement in nursing is summarized by Deloughery (1977: 3): "To study the history of nursing is to study world events, as well as trends of thought and action as they have influenced nursing's evolution".

1.1. The early history of the Catholic Church caring for the sick

Nurse historian, Patricia Donahue (1985: 93) is of the opinion that the history of nursing first became continuous with the beginning of Christianity, as pre-Christian records were fragmented and scattered. This section will look at the relationship between Christianity (the Church) and nursing.

1.1.1. The Early Christian era: 1-500 AD.

The first five centuries of the Christian era witnessed the rise of a religious and social movement that enabled the systematic development of organized nursing (Donahue, 1985: 101; Mellish, 1985: 26). Jesus Christ set the example and many of his followers (Christians) assumed the responsibility for the care of the sick. This is apparent in various texts in the Bible, the most authoritative book for Christianity. Some examples of these texts are:

- ✓ "Jesus went about all the cities and villages, … and healed every sickness and every disease among the people". Matthew 9:35 (New King James Version, 1982: 1162).
- ✓ "You shall love your neighbor as yourself". Mathew 22:39 (New King James Version, 1982: 1183).
- ✓ "Assuredly, I say to you, inasmuch as you did it to one of the least of these, My brethren, you did it to Me". Matthew 25:40 (New King James Version, 1982: 1187).

Searle (1965: 134) has pointed out that the above mentioned Christian concepts have inspired men and women to devote their lives to the care of the sick from the days of St Paul who praised Phoebe, the deaconess "… for indeed she has been a helper of many…". Romans 16:1 (New King James Version, 1982: 1386).

Deaconesses, widows and nuns were the earliest orders of women workers involved with nursing (O'Brien, 2008: 25; Masters, 2005: 7; Mellish, 1985: 28). Single women were provided with the opportunity to be useful and responsible, opening the door to respected works and laying the foundations of the 'nurses' calling and all modern works of charity (Donahue, 1985: 101).

Two of the famous women who devoted their time to the sick were Phoebe and Marcella. *Phoebe* (Phoebe, 60 AD), a friend of St Paul, the first deaconess and the "first district or visiting nurse (Miller, 2004: 310; Donahue, 1985: 104; Mellish, 1985: 28; New King James Version, 1982: 1386). *Marcella* (St Marcella 410 AD) was a Roman matron. The Roman matrons were known in the Catholic Church for devoting themselves to the care of the sick during the fourth and fifth centuries. Marcella converted her palace into a monastery, which led to her titles of Mother of Nuns and founder of Convents in the West She encouraged other intelligent and spiritually inclined Roman matrons to join her. Marcella instructed her followers in the care of the sick, while devoting her time to charitable work, prayer, and study (O'Brien, 2008: 26, 27; Donahue, 1985: 107, 108; Mellish, 1985: 29).

1.1.2. The Early Middle Ages (Dark Ages): 500 - 1000 AD

Donahue (1985: 123) explains that during the Dark Ages the domination of society by the Church was practically unchallenged. The Roman Empire was crumbling. Chaos reigned supreme as a result of the impact of the onslaughts of barbarian tribes, extreme moral decay, widespread epidemics, natural disasters and wars. Life became increasingly dangerous, and necessitated the formation of protective groups, and people gathered together in search of safety, as people lost their sense of security (Donahue, 1985: 123; Mellish, 1985: 32).

During this time *Monasticism* was born out of the desire of many Christians to lead lives of sanctity. With the beginning of communities like those of St Benedict of Nursia, the care of the sick became a more significant part of their work (O'Brien, 2008: 26, 27; Mellish, 1985: 32, 33). In Chapter 36 of the "Rule of St Benedict" he taught his brethren: "Before and above all things, care must be taken of the sick that they be served in every truth as Christ is served" (Verheyen, 1949: online).

Monastic houses for women (later called convents) grew in number during the sixth and seventh centuries. The women in these monasteries were sheltered by a rule, approved by the Church, providing safety and the freedom to lead the occupational calling of their choice (Donahue, 1985: 129; Mellish, 1985: 29). Scripture reading, the study of ancient literature, the transcription of manuscripts and the performance of drama were important activities in these communities, but the care of the sick was often the chief function. One such monastery was the Holy Cross Monastery founded by St Radegunde (O'Brien, 2008: 28; Mellish, 1985: 33).

1.1.3. The Late Middle Ages: 1000 - 1500 AD

By the late Middle Ages many barbarian tribes had settled somewhere in Europe, staked claims to lands, and often had been Christianized and civilized (Donahue, 1985: 140). Trade promoted the development of inland cities and a new middle class. The castle and monastery walls which had previously offered protection became a liability due to infection control problems (Masters, 2005: 7; Donahue, 1985: 140). The gates in the walls were secured and the bridges over the moats were raised. In many instances the walled cities were overpopulated. There were limited, if any, facilities for the provision of clean water and food or sanitation, making infection control nearly impossible. Social groupings for nursing occurred, with the rapid spread of disease and the fear associated with the plagues. Religious zeal escalated and lead to the development of different types of care than what had been required when monasteries were the focal points of the communities.

As care was needed outside the monasteries, religious missionary bodies arose. Religion and nursing were taken out among the people. According to Robinson (1909: online) and Donahue (1985: 140), St Francis of Assisi (1182-1226), the personification of this approach, instituted three religious orders: the first order, Friars Minor (for male Religious, monks); the second, Poor Clares (for female Religious, nuns); and the third, Tertiaries, for lay men and women who wished to continue to lead secular lives (O'Brien, 2008: 33; Mellish, 1985: 38). St Francis is best known for his care of lepers. This disease could be compared to modern-day HIV (Grigsby, 2004: 59).

In the late Middle Ages the concept of free-standing institutions (hospitals) to care for the mentally and physically ill began to emerge. These facilities were started and staffed by Religious men and women (O'Brien, 2008: 29). Pope Innocent III encouraged the development of hospitals in European cities. He built the Santo Spirito Hospital in Sassia, which became the model of all future city hospitals, and encouraged others to organize similar institutions in their own communities (Ott, 2009: online). This idea of city hospitals was met with support and approval, and in some cases hospitals passed cordially from religious to secular control (Donahue, 1985: 170, 171).

In 1347, a plague of the bubonic type, swept over Europe and killed a third of the population (25 million people) in five years. Priests and nuns were left to care for the sick. Monasteries and convents were soon deserted, as they were stricken, too. Tremendous changes took place as a peasant revolt broke out in England, France, Belgium and Italy due to the changing needs of society, prompting the beginning of reforms (The middle ages.net, 2011: online; Donahue, 1985: 182, 183).

1.1.4. Renaissance and Reformation.

Before the Reformation, all nursing of the poor in Europe was done by the various Catholic orders. With the Reformation came the suppression of these Religious Orders in England, Germany and other parts of Western Europe (Searle, 1965: 134). The sixteenth century belonged to two immense movements, the Renaissance and the Reformation (Donahue, 1985: 188; Mellish, 1985: 39-41).

The chaos of the Middle Ages subsided with the unparalleled phenomenon known as the Renaissance. It was a period characterized by shifts in standards and with a decline in the power of the Church, accompanied by a rise in intense secular awareness. It was also known as the time of Humanism. Donahue (1985: 188) viewed the Renaissance as both a blessing and a curse, as it had both a positive influence on the medical advancements and negative influences as it led to the renewal of pagan superstitious practices and witchcraft (Masters, 2005: 9). Among the advancements were the hundreds of drawings Leonardo da Vinci (1452 – 1519) produced of the human anatomy, during this period.

The Reformation (Protestant Revolt), which began in 1517, started as a reform and ended as a revolt. It was a religious movement that resulted in a division in Christianity with extensive consequences for healthcare. The rebellion against the Pope and the patriarchal rule of the Catholic Church was led by Martin Luther. These separatists were called Protestants, a group of discontented people who broke away from the Catholic Church (Donahue, 1985: 191). The Lutherans (followers of Luther) declared their independence from the Pope and the right of each state to choose between the new Church and the old. This movement divided Europe in two. Within a few years, other revolts against Catholic authority were encouraged by Lutheranism. During the next century many divisions arose, such as the Anabaptists, Mennonites, Quakers, Calvinists, Presbyterians, Puritans and Anglicans. Each interpreted the doctrine in a different way but they were all as intolerant to opposition as they were to Catholicism. Corrections of abuses within the Catholic Church came to an end with the Council of Trent (1545 – 1563), where Christian theology was re-defined. These efforts, called the Counter-Reformation, failed to reconcile Catholicism and Protestantism. Europe drifted into a tragic struggle between the two groups and the Thirty Years' War (1618 – 1648) between Catholics and Protestants followed (Donahue, 1985: 192, 193).

Little effect on healthcare as a result of the Reformation was felt in Catholic countries as nursing continued to be done by the Religious. The sixteenth century also saw renewed activity in nursing within the Catholic Church with more than a hundred Religious Orders, devoted to this cause, originating in this period (Mellish, 1985: 53). This was, however, not the case in Protestant countries.

1.1.5. Care in Protestant countries

Donahue (1985: 193) has called the period between 1550 and 1850 the "Dark Period of Nursing" as only some hospitals in the Protestant countries survived when the Religious (monks and nuns) were driven out of institutions. In England alone, a hundred hospitals were closed, and for a while there was little if any provision for institutional care for the sick (Deloughery, 1977: 23). To meet the great need of the sick poor, for shelter and treatment, the State, or its local authorities, and later voluntary charitable organizations, undertook the management and control of hospitals. To meet the subsequent shortage of people to care for the sick and the poor, secular nurses had to be found to replace the Religious in the hospitals. The new type of nurses had no experience of hospital work, nor was training provided. The monks and nuns had worked in the hospitals, for religious reasons and on humanitarian grounds, but the new type of nurse came into the hospitals for economic reasons. Hospitals became places of horror. A period of stagnation had set in, and no progress was made in the art of nursing in the Protestant countries, until the nineteenth century (Donahue, 1985: 193, 224; Mellish, 1985: 45; Searle, 1965: 134).

During the nineteenth century, deaconess orders were established by the Protestant Church. This movement set the stage for the founding of a new system of nursing by Florence Nightingale (1820-1910), whose reforms significantly changed nursing and the care of the sick (Donahue, 1985: 238, 239). According to the standard histories, nursing had fallen into a trough of inefficiency and immorality by the nineteenth century. Miss Nightingale stated that nursing was generally done by those "who were too dull, too weak, too drunken, too dirty, too old, or too bad to do anything else" (Abel-Smith, 1960: 4).

The introduction of training was the main focus in the reform of nursing in the second half of the nineteenth century. It involved changes in recruitment, organization, and in the system of hospital administration. Wider medical knowledge and care were available and doctors started to recognize the importance of the bedside care given to patients (Abel-Smith, 1960: 17).

As with the rest of the world, history would influence the introduction and development of nursing in South Africa.

1.2. South Africa

Before Christ, the Southern tip of Africa was occupied by primitive groups that had one or another form of social grouping (Mellish, 1985: 23). In these groupings the "oermoeder" or witchdoctor played the main role in healing. This would all change with the arrival of Western nations.

1.2.1. The sea-route to India

In search of gold and spices the Portuguese ventured away from their homes during the 15th century to avoid the hazardous overland trips to Venice, as trade between the West and the East became increasingly important (Wilson, 2009: 43, 45). To circumvent the Moslem traders, who controlled the camel routes to the East, the Western nations tried to find a sea-route to India around the African continent in order to divert the wealth of the East to the West Bartholomeus Diaz sailed around the Cape of Storms (later named the Cape of Good Hope) during July 1487, but it would be Vasco da Gama who finally sailed around the Cape and arrived in Calicut (India) on 23 May 1498 (Wilson, 2009: 44; Mellish, 1985: 46; Searle, 1965: 9, 10).

High death rates made forts and refreshment stations necessary to retain crews. In 1505 the uninhabited Island of St Helena was occupied to develop a refreshment station. More fords and trading centers followed along the route, but were found inadequate. Deterioration in the health of the crews necessitated a hospital, and in March 1508, the first hospital on African soil was built within the fortress of Mozambique. Slaves attended to the sick, and due to the poor care mortality rates stayed high (Searle, 1965: 8).

By the turn of the 17th century, the Netherlands was able to force its way into the spice trade and, due to its geographical position, was able to become a great retailing carrier of goods between the East and the rest of Europe, and had gained sufficient naval dominance in the Indian Ocean to establish the East Indian Company (Wilson, 2009: 45). William of Spain annexed Portugal during this time and for political reasons he closed the Port of Lisbon to all Dutch shipping. The only answer for the Netherlands was to find the sea-route to India (Searle, 1965: 11). In doing so, the Dutch, like the Portuguese, found that the death rates at sea were as high as 44% (1648) per voyage (Searle, 1965: 14). The loss of life was high as a result of the limited and stale food supplies, poor hygiene and excessive exposure to the elements, and due to the battles they fought with the Moslem traders (Searle, 1965: 10). This posed a new threat to wealth for European nations.

The founding of a Western nation at the southernmost tip of Africa became necessary to sustain East-bound voyages to India (Searle, 1965: 8). The Dutch knew this was possible as Dutch fleets had to stay over in the Cape on three occasions. In December 1601, Joris van Spilbergen, with a fleet of three vessels, cast anchor at “the watering place of the Saldanha” (later called Table Bay). The sick were conveyed to the land where a temporary hospital was established and hereby the death rate was reduced (Searle, 1965: 20). Later, on two occasions (1627 and 1648), the Dutch had to stay at Table Bay again. In March 1651, the surgeon Johann van Riebeeck was appointed by the Council of

Seventeen, to establish a station at the Cape (Searle, 1965: 21). On 5 April 1652, Johann van Riebeeck and his crew arrived at the Cape (Searle, 1965: 23).

The motivation for establishing refreshment stations, and later the forming of a Western nation in the southern tip of Africa, was primarily stimulated by trade (economic) considerations with health as a secondary "coincidence" (Mellish, 1985: 47). Economic motivations thus influenced decisions and funding for the station. Even though one of Van Riebeeck's tasks was to establish a hospital for the Dutch, the motivation was not to improve health as much as it was to protect the Dutch's trade interest. The subsequent colonizing of the Cape and areas north of the Cape, was not aimed to civilize the population of Southern Africa, but mainly motivated by the economic gain that could be made. From the beginning, Van Riebeeck's task was difficult as health problems arose because of foul weather, inadequate shelter and a shortage of food. Within months of their arrival two ships arrived with many sick on board, requiring immediate action. There was also a serious lack of skilled staff: only two surgeons were appointed by the Company, one of them a mere apprentice. To make matters worse, both surgeons became seriously ill at the same time (Mellish, 1985: 47).

At this time, great charitable nursing orders for men and women were flourishing in Catholic Europe. Catholic Religious (monks and nuns), bound by religious vows, were staffing the hospitals and were caring for the sick poor in their homes. With the discoverers crossing the Atlantic, Religious were going out as missionaries, offering nursing services to the trading companies. The possibility of acquiring such assistance for the sick, did not arise at the Cape until two centuries later, as the Nursing Orders of that time were all of the Catholic faith, and as the Netherlands was a stronghold of the Protestant faith upholding the tenets of the Reformed Religion, the Catholic orders were not accepted at first (Searle, 1965: 23-26).

1.3. The beginnings of the Catholic Church in South Africa

The first record of a Catholic presence in South Africa was of a service held, following the erection of the Padrao of St Gregory by Bartholomew Diaz on Santo Cruz island, near Algoa Bay, in 1487 (Mc Donagh, 1983: 42). However, a continuous presence of Western inhabitants was only established in the 1600s, with the establishment of a station at the Cape by the Dutch East Indian Company.

The Dutch Calvinists who settled at the Cape were heirs of the Protestant Reformation. Memories of the Thirty Years War (1618 – 1648) in Europe between the Catholics and the Protestants were still vivid. The Dutch also struggled bitterly against Catholic Spain for independence (De Gruchy, 1982: 74). Catholicism was therefore forbidden in South Africa between 1652 and 1795 under Dutch rule (Southern African Catholic Bishops' Conference, 2004: 67).

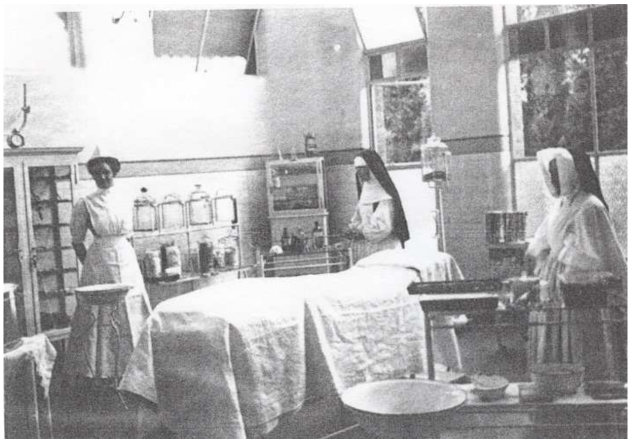
Prior to 1795, only occasional visits of priests traveling on Portuguese or French boats were allowed to set foot on Cape soil. The same attitude prevailed between 1795 and 1802 under British rule. With the adoption of the "Kerkorde" in 1804, the Dutch government opted for religious toleration of the Catholic faith (and other groups who "acknowledged a supreme being"). Three Dutch priests arrived in Cape Town, but they were sent back to the Netherlands when the Cape returned to the British rule two years later (Southern African Catholic Bishops' Conference, 2004: 67; Mc Donagh, 1983: 43, 44). In 1814, the British Colonial Office refused permission for the first priest appointed to the Cape of Good Hope to take up residence at the Cape. He took up residence in Mauritius. No Religious father was allowed to stay in the country until 1819 (Brain, 1996: 16).

Recognition from the British Government was received by 1820, when Father (Fr) Scully was allowed into the country and a Catholic Church was built in

Harrington Street, Cape Town. In 1837, at the request of the Cape Town community, the Vatican appointed an Irish Dominican, Patrick Griffith, as the first Bishop of South Africa. Under his guidance the Catholic Church began to grow (Southern African Catholic Bishops' Conference, 2004: 67).

The Church grew slowly and its influence gradually spread as the Western population moved east By 1847 the need arose for the vicariate (Church region) to be divided, as the area the Religious had to cover, became too big to handle. A decision was made to divide the vicariate into two parts, the Western Vicariate (around Cape Town) and the Eastern Vicariate (around Grahamstown). In **1849** the new Bishop (Aidan Devereux) for the Eastern Vicariate brought a group of Religious Fathers, a party of **six Assumption Sisters**, and some lay helpers to South Africa (Brain, 1996: 16, 17). These sisters were the first Catholic Religious Sisters to arrive in South Africa (Southern African Catholic Bishops' Conference, 2004: 67).

By the middle of the 1800s very little had been done for the indigenous people in South Africa. The first attempts by the Catholic Church to convert the indigenous people outside the boundaries of the Colony were made by Bishop Jean-François Allard of the Natal Vicariate in 1854. Several attempts to work among the Zulu nation failed (Southern African Catholic Bishops' Conference, 2004: 68; Mc Donagh, 1983: 47). The first significant results among the Zulus were accomplished by the **Trappists of Mariannhill** in the 1880s (Mc Donagh, 1983: 48). Under leadership of **Abbot Francis Pfanner**, the Trappists developed innovative missionary methods, combining farming, schooling and preaching (Southern African Catholic Bishops' Conference, 2004: 68). In the meantime missionary work spread to Bloemfontein. After the discovery of diamonds on the banks of the Vaal River missionaries moved to the Transvaal. Other mission stations were opened as more gold was discovered (Southern African Catholic Bishops' Conference, 2004: 68). Religious Sisters assisted with nursing care in the diamond and gold fields. One example was the Holy Family Sisters (see Photo 1.1), who managed the Johannesburg Hospital between 1887 and 1915 (Mc Donagh, 1983: 56; Searle, 1965: 157).



Photograph 1.1 Sisters of the Holy Cross in Johannesburg (courtesy of CATHCA)

By the nineteenth century there was a great movement in Europe to send missionaries to distant continents to preach the gospel and convert the people to Christ (Mashaba, 1995: 3). Medical missions were set up in South Africa by most Church denominations. The London Missionary Society, the Anglican Church and the Church of Scotland were very early in the field, whilst others appeared later. The Catholic Church and the Dutch Reformed Church entered the missionary scene late, but were later credited with half of the health services in-country (Gelfand, 1984: 25). Throughout the 20th century, the Catholic Church showed remarkable signs of growth in Southern Africa, particularly just before and after the Second World War. Long seen as a foreign Church, it gained influence in all sectors of society up to the point where it is now the second biggest Church in South Africa (Southern African Catholic Bishops' Conference, 2004: 68; Mc Donagh, 1983: 47).

Searle (1965: 134) stated that "due to the influence of Religious Sisterhoods (referring to both Anglican and Catholic Sisterhoods) the teaching of Christ formed the hard core of the ethical concepts of the nursing profession, in all lands where the Christian religion is paramount, as it was the driving force in all nurse/missionary effort."

1.4. Catholic healthcare in South Africa

The beginning of Catholic healthcare started with the arrival of Religious Orders in South Africa in December 1849. Although these Religious Orders mainly came to South Africa to provide teaching services as their primary function, nursing soon occupied as much of their time and attention as teaching. Soon after the first group of Religious Sisters arrived, they established dispensaries (clinics) and hospitals as part of their mission effort (Searle, 1965: 153, 154).

Mission stations were established in South Africa by a number of European Religious societies. The **general pattern** involved the establishment of self-supporting isolated mission communities. The mission stations consisted of the Church building, school building, and sometimes a hospital, as well as residences for missionaries and other people. The establishment of missions led to the provision of education facilities for black pupils, as well as to the establishment of hospitals and healthcare facilities for black communities. A cardinal feature of the medical mission in South Africa is the leading part taken by the nursing sisters. The Sisters often founded the mission, set up a dispensary or clinic or even ran a hospital for years without a doctor on the station. In some instances either no doctor was appointed to the station or the station was merely visited at regular intervals by the district surgeon of that area (Gelfand, 1984: 21).

Searle (1965: 158) acknowledged the contribution the Church made by writing that "the Roman Catholic Sisterhoods of the 19th century made a lasting contribution to the development of nursing and health services in South Africa. They went where their help was needed, opened emergency hospitals, helped to develop these permanent services, and consolidated the future of nursing by introducing the training of nurses into the hospitals they helped found."

In his book dedicated to Christian doctors and nurses, Gelfand (1984: 20) remarked that the Catholic Church established a "most impressive missionary service in South Africa". He explains that the majority of the medical missions and clinics were founded in the midst of the tribal lands with the purpose of rendering aid to those whose need was greatest The populations of these areas were poor and, as a rule, had no other medical facilities than those of the local traditional herbalists. When the medical missions started, very few of the Africans had come into contact with Western civilization.

The scenario changed over the period of the next thirty years. Mines and industries sprang up in South Africa. Men brought back something of the new world as they were affected by Western influence while working away from home in these mines and industries. The hundreds of mission schools provided thousands of Africans with a good educational background, leading to a better understanding and appreciation of the health services. This increased the need for more nursing care, improved hospital construction, diagnostic and therapeutic processes (Gelfand, 1984: 148).

In the early twentieth century, medical missions became efficient institutions. They added better buildings with good theaters, X-ray departments and laboratories and, last but not least, more qualified nurses and generally a training school for African nurses (Gelfand, 1984: 30, 70). During the pioneer period the development of the missions depended almost entirely on the resources of the Church sponsoring the particular mission, often resulting in financial hardship (Gelfand, 1984: 147).

1.4.1. Catholic hospitals

The medical missionaries answered to the need of the African population. As towns in South African areas grew, hospitals were erected by the provincial administrations according to the needs of each region. These catered mostly for the white population and, to a lesser extent, for the colored and Indian people. Very little was done for the native inhabitants living in their tribal lands. District surgeons could be called upon to deal with the spread of contagious diseases, but the individual sick were largely unattended, as a hospital or clinic for sick Africans were very scarce. It was left to the missionaries to provide these services (Gelfand, 1984: 21). By 1914, the government had not established a single rural hospital for black patients (CATHCA, 2011: 50). However, the Catholic Church provided healthcare in numerous areas, mainly in the black areas. Adequate funding was an ongoing concern.

1.4.2. The period of government support

By 1935 the government was beginning to accept the fact that health was part of its responsibility (Gelfand, 1984: 148). Until this time, it had not entirely agreed with this principle. Prior to 1935, the government only provided the district surgeon, and hospitals in white areas, but thereafter significant contributions towards patient care in mission hospitals (based mostly in black areas) were made. Within a relatively short time the government grants became a substantial portion of the hospitals' funding and they were able to expand, provide more nursing care, prescribe the expensive modern drug therapy and carry out more elaborate special investigations. With more funds available the missions also started to establish clinics in the outlying areas and to bring care closer to the people's homes. A number of these clinics (dispensaries) were started in the earlier pioneering period, but with more money available they grew and multiplied around every large mission hospital (Gelfand, 1984: 148).

During the period 1935 to 1973, a remarkable development in mission hospitals took place in the tribal lands where millions of Africans lived, providing the vast areas with hospitals and clinics. Missionaries successfully set up a health service in what was eventually to become the Black Homelands of South Africa (Gelfand, 1984: 147).

Many of the mission hospitals were becoming big training institutions for nurses, and in the 1950s and 1960s, hundreds of nurses were undergoing training in the mission institutions throughout the country (Gelfand, 1984: 148).

1.4.3. Training of nurses

The first trained black nurse employed in the medical mission of Mariannhill was Sister (Sr) Bernadette. She went to the Catholic School in Mariannhill and in 1927 she passed her examinations in general nursing and midwifery, and received an appointment as a nurse in the Mariannhill Hospital (Schimlek, 1950: 55).

As the mission hospitals were established they stared training nurses. The training was expensive and hospitals' traditional stream of funding, from overseas funders, was no longer sufficient and the administrators applied for funding from government. In 1929, the then Native Affairs Department started funding the training for local women at the mission hospitals, with the purpose of training them to take over the mission hospitals (CATHCA, 2011: 50). Photo 1.2

illustrates nurses in training at St Apollinaris Hospital (one of the many Catholic nursing schools).

However, it is not known how many nurses were trained at the mission hospitals. In 1951 alone, over 500 black nurses were in training at 22 recognized mission nursing schools (eight preparing candidates for the Nursing Council Certificate and 14 for the Natal Nursing Certificate) (CATHCA, 2011: 50) .

Photograph 1.2 Auxiliary nurses in training at St Apollinaris Hospital (courtesy Sr Winifred)

1.4.4. Changing times

The legacy of differentiating between people on the basis of color in South Africa started at the birth of the Union in 1909, when Britain drew up the Act of the Union, and added a color bar in the constitution (Arnold, 2005: 330). Power was handed over by the British government to the white minority, without safeguarding the future of the black majority. The four South African colonies came together under the Union of South Africa in 1910. The years 1910 to 1948 were known as the era of segregation (Thompson, 2000: 150), and the white minority had a monopoly on political representation (Omer-Cooper, 1994: 158). By 1913, the Natives Land Act was passed and it limited African land ownership to the reserves (Arnold, 2005: 330). Hereafter the government continued to apply a comprehensive program of racial segregation and discrimination (Thompson, 2000: xv, 158). After 1948, the National Party instituted comprehensive apartheid (Arnold, 2005: 330). The Southern African Catholic Bishop's Conference (SACBC), established in 1947 (Brain, 2002: 106), made its first declaration against racism in 1952 and condemned apartheid further in 1957 (Southern African Catholic Bishops' Conference, 2011: 120).

Prime-minister Verwoerd formalized his policy of "separate development" by 1958 and two years later the homelands (Bantustans) were created: Bophutatswana, Ciskei, Gazankulu, kaNgwane, kwaNdebele, KwaZulu, Lebowa, QwaQwa, Transkei and Venda. This limited the African population to 13% of the country (Arnold, 2005: 337). The homelands were scattered throughout the eastern half of South Africa and hugely inadequate to sustain the people living there (Thompson, 2000: 159). Black Africans were only allowed to visit the rest of South Africa as "guest workers". The most dramatic aspect of the homelands policy was the mass removal of the African population to their homelands.

Photograph 1.3 Forced removals of black Africans from white areas (Courtesy CATHCA).

Between 1960 and 1983 more than three and a half million (3,548,900) people were removed as part of the Surplus People Project, removing black people from white areas, as illustrated in Photo 1.3 (Arnold, 2005: 335). The homeland policy and other apartheid policies had a severe impact on mission work. It dictated where people could live (many of the Religious were white Europeans living in black areas), and who they could teach/treat. During the first decades of apartheid, the Church often adopted a non-confrontational stance towards the government, in the hope of maintaining the Church's network of schools, hospitals and welfare institutions (Southern African Catholic Bishops' Conference, 2004: 69). There were 4,360 Catholic Schools in South Africa by 1945 (Higgs and Evans, 2008: 503). Catholic schools in South Africa were forced to stick to the race segregation laws, which were introduced after 1948, in order to avoid being closed down (Godfrey, 1995: 508).

After the initial boom in Catholic healthcare, progress was threatened, by 1943, with the implementation of the policy on **National Health and Hospital services for all**. In response to this policy change, Archbishop Lucas Martin set up a Catholic Hospital Board in 1946 to represent the mission hospitals, to fight for the independence of the hospitals, as well as to advocate for poorer rural hospitals to access government subsidies. The board also formed a Nursing Committee to enhance nurses' training at the mission hospitals. These measures were beneficial to the mission hospitals and the hospitals prospered (CATHCA, 2008: 8).

Catholic hospitals and schools came under threat again in the 1970s, with the government focusing on the Church. In 1973, the government introduced the "**Government Comprehensive Health Service scheme**" to be implemented in all government-aided hospitals and clinics. All government-aided institutions (including the aid dependent Catholic hospitals) were obliged to provide both advice and equipment for contraception, which conflicted with Catholic teaching on birth control. Therefore the government decided in 1973 to take over all Catholic hospitals, in "homeland territories". The take-over did not only affect the Religious working in the hospitals, but also the student nurses in training at these facilities. Take-overs started in Transkei by 1974, followed by Bophutatswana, Lebowa and Ciskei and finally kwaZulu-Natal (KZN) in 1978 (CATHCA, 2008: 8). St Mary's Hospital in Mariannhill is the only rural Catholic hospital that remained in Catholic Control (see dwindling numbers of hospitals in section 1.4.1). Hospitals in the urban areas soon felt the financial pressure due to fewer Religious Sisters from overseas being available to staff the hospitals, and the competition of newly founded privately owned hospitals (CATHCA, 2008: 8; Godfrey, 1995: 508). It was a crisis point for Catholic healthcare in South Africa as nearly all the hospitals were taken over, closed or sold. Ultimately only two hospitals "survived", St Mary's Hospital in Mariannhill (now a semi-government funded District hospital) and St Vincent's Hospital in Bela-Bela (a private hospital) (CATHCA, 2011: 120). It is doubtful if the hospitals would have been able to operate in the long-term, due to escalating costs, shortage of trained staff, duplication of services and the decrease in the number of Religious Sisters (CATHCA, 2011: 119).

The Catholic Directories (report on the structures of the Church) between 1936 and 1988 depict the changing picture of Catholic-managed health institutions. In 1935 there were 103 mission hospitals. The number of clinics (dispensaries) was not listed and might be included in the 103 (Salesian Institute, 1935: 2). Two decades later in 1954, 48 hospitals remained and a large number (178) of clinics were listed (Salesian Institute, 1954: 2). The picture remained stable for the next two decades and by 1974, 46 hospitals and 169 clinics were listed (Southern African Catholic Bishops' Conference, 1976: 245). The 1970s, however, had a devastating effect on the hospitals as in 1987, only 15 hospitals were recorded and no clinics were listed (Southern African Catholic Bishops' Conference, 1988: 73-75).

In 1988, Sr Shelagh Mary Waspe (a Holy Family Sister) started an undertaking "*to look after Catholic healthcare interests*", which evolved into the Catholic healthcare Association (CATHCA). CATHCA's mission is to "*affirm, develop,* *support and strengthen both individual healthcare workers* (HCWs) *and the evolving Catholic healthcare network, in conjunction with all other healthcare role-players*" (CATHCA, 2011: 124, 126). CATHCA (2011: 125) describes how the formal institutions declined after the 1980s, and how a vast number of new grass-roots initiatives have begun. Catholics **rediscovered their role in healthcare**, not through hospitals, but through their home-based care (HBC) projects (Parry, 2005: 45). Although many clinics still exist the Catholic healthcare response's backbone consists of HBC projects throughout the country. By 2010, CATHCA represented more than 160 organizations of which two are hospitals, 38 clinics, 16 hospices, eight orphanages, eight multipurpose healthcare centers, six health training institutions and more than 80 HBC projects (CATHCA, 2011: 126, 127). CATHCA funds HBC training for rural HBC-workers, provides capacity building and skills training, advocacy on ethical issues, provides health information and coordinates regional conferences and workshops for their members. Many of these organizations provide a response to the Acquired immune deficiency syndrome (AIDS) epidemic.

1.4.5. HIV care and support

In response to the AIDS epidemic and its severity in the region, the SACBC, as the governing body of the Church in Southern Africa, by 1999, set up an office to spearhead an effective response to the crisis. Sr Alison Munro (an Oakford Dominican Sister), assisted by Bishop Kevin Dowling from the Diocese of Rustenburg, was appointed as the Director of the AIDS Office (CATHCA, 2011: 124). The role of the AIDS Office is to:

- ✓ Support diocesan (Church region) and parish projects around prevention, care of the sick and dying, orphan care and treatment, through some 200 initiatives (Parry, 2005: 43).
- ✓ Urge the spiritual care and support of people affected by HIV & AIDS.

- ✓ Promote advocacy around care for children and access to treatment.
- ✓ Work with other people of good will, non-government organizations (NGOs), other churches and government departments.
- ✓ Facilitate training and capacity building in project and financial management, prevention, HIV & AIDS care, care and support for children, delivery of treatment, spiritual and pastoral support (Munro, 2006b: 1; Munro, 2002: 400).

Perry (2005: 47) summarized the Church's stance as: " *If the Church is really going to be* **relevant in the era of HIV & AIDS**, *it cannot turn away from any possibilities of showing holistic care and support to communities, especially the poorest of the poor and the most marginalized*".

As part of the effort to provide holistic care and support to communities, plans for implementation of an antiretroviral treatment (ART) program in Catholic facilities started in 2003. From the initiatives within the Church, 22 Catholic facilities were selected and funding proposals were submitted. With Cordaid (Dutch funder) funding, the AIDS Office started training HCWs in February 2004 who initiated treatment at eight of the facilities. Activities could be scaled-up significantly by the end of 2004 when funding by the United States of America (USA) President's Emergency Plan for AIDS Relief (PEPFAR) to Catholic Relief Services (CRS) became available for treatment (Parry, 2005: 47). The SACBC AIDS Office sucessfully implemented the ART program, and by 2009 the leadership of the program was transitioned from CRS (an international organization) to the SACBC AIDS Office (a local South African organization). This study will focus on this ART program.

The projects that are rolled out by the ART program varied in many ways. To illustrate the case in point, four of the ART projects' background will be discussed briefly.

1.5. Four HIV projects

As Catholic healthcare rediscovered its role, in order to stay relevant in the era of HIV & AIDS, projects evolved in different ways. This can be seen in the case of the four projects selected for study in this thesis.

- ✓ Centocow Mission, Creighton. This project, based in a former Catholic Hospital, was taken over by the government. The St. Apollinaris Hospital is a district hospital providing inpatient and outpatient care. Even though the hospital was no longer managed by the Religious, the mission activities around it continued. Today an NGO, founded by the Church, and the government closely collaborate in providing ART.
- ✓ Sisters of Mercy, Winterveldt. A group of Religious Sisters, during the 1980s, started a development project in the former homeland of Bophutatswana that was at the time characterized by political turmoil. ART is provided from the Mercy Clinic as the main Centre in a network of six primary healthcare (PHC) clinics.
- ✓ Tapologo, Rustenburg. In the 1990s, a diocesan order (Religious community of men and women from a local church region) started providing PHC to people in informal villages around the Platinum mines. A large HIV response developed because of the overwhelming need for care in these communities. Apart from ART the project provides PHC, HBC, Orphan care and inpatient hospice care.
- ✓ HIV & AIDS Prevention Group, Bela-Bela. A church volunteer initiated a group that evolved from initially providing HIV awareness to becoming a specialist driven ART clinic. The project supports tuberculosis (TB) care, HBC and Orphan care.

1.5.1. Centocow Mission, Creighton

Trappist missionaries set up mission stations throughout KZN (see section 1.3). At first, the Trappists would concentrate on making gardens and erecting the necessary buildings. Thereafter, full scale evangelization started. Shortly after the missions opened, Sisters of the Precious Blood begun to visit the huts in the area; a school and healthcare would follow (Brain, 2004: 23).

Centocow Mission was established in 1888, on a farm, Dronkvlei, in the Creighton district of southern KZN (Dischl, 1983: 10), situated on the edge of an indigenous forest, on the west bank of the Umzimkulu river (Brain, 2004: 23). Money for the purchase of the land was donated by a Polish princess, and therefore the mission was named after the Polish shrine and place of pilgrimage, Czenstochova (Brain, 2004: 24). From the beginning, efforts were made to help the sick and injured Africans who came to the mission. In 1926, Dr Kohler, a German mission doctor, joined the Centocow Mission and opened an out-patient department. He began by taking African in-patients into a small 2-room shack with only six beds, attached to the mission. By 1931 it has grown sufficiently to accept 36 patients (Gelfand, 1984: 212). Fr Apollinaris Schwamberger was anxious to provide better medical facilities, and in 1936 the foundation stone was laid for the new hospital. Shortly before the completion of the hospital, Fr Apollinaris died unexpectedly and the hospital was named after him. Between 1938 and the 1980s, St Apollinaris Hospital was staffed by the Precious Blood Sisters, with assistance from the Sisters of the Daughters of St Francis of Assisi from 1953 (Brain, 2004: 29). Photo 1.4 shows Sr Winifred (the last Catholic matron of St Apollinaris Hospital) and Dr Kops on their way to an outstation (satellite), on foot, walking for hours to assist the sick. Sr Winifred Fockele, commenced duties on 15 January 1977 and worked until she requested to be pensioned on 31 March 1999 (kwaZulu-Natal Department of Health, 2001: online).

Photograph 1.4 Sr Winifred and Dr Kops walking to an outstation 1962-1963 (Courtesy Sr Winifred)

Soon after the opening of the hospital, a training school for nurse-aides was started. Later, in line with the South African Nursing Council's (SANC) requirements, a teaching course for assistant nurses was introduced (Brain, 2004: 57).

St Apollinaris Hospital was taken over by the government in the 1980s. Thereafter activities at the mission diminished. After the Trappists could no longer fulfill their religious responsibilities, the Centocow mission was handed over to a group of Polish fathers. A small group of Pauline fathers arrived in South Africa in 1991 (Brain, 2004: 131). By then the St Apollinaris Hospital was managed by the government, but the fathers continued the mission work. Fr Ignacy (Ignatius) designed and opened additional outstations (satellite churches) and, after noticing the need for recreation, organized soccer teams for young men, built a soccer field and started a soccer league (Brain, 2004: 141). Izandla Zothando (now named Centocow Development Program) was established in 2000 under the auspices of Fr Stanley Dziuba (now Bishop of the Diocese), to provide holistic HBC for people with HIV & AIDS, their families and communities (Catholic Relief Services, 2004: 1). Thirty-three villages in the rural, mountainous area were covered.

Through collaboration between the government-managed St Apollinaris Hospital and the Catholic-managed NGO, Izandla Zothando, the Ethembeni ART clinic opened on 4 October 2004 (St Apollinaris Hospital, 2005a: 6). Through PEPFAR funding the NGO has been able to fund salaries for staff and infrastructure, while the government has paid some salaries as well as the ART drugs and the laboratory services (St Appolinaris Hospital, 2005b: online)

1.5.2. Sisters of Mercy, Winterveldt

The Sisters of Mercy (Johannesburg) was founded by five sisters who arrived in Cape Town in October 1897 (Higgs and Evans, 2008: 501). Initial assistance was given in Kimberley where diamonds had just been discovered. Subsequently a convent was built in Mafikeng and by 1899 the Sisters could settle there (Sisters of Mercy, n.d a: 3). Education was the Sisters main focus. By 1907, they took over a school, previously run by the Ursulines, and established themselves in Braamfontein, Johannesburg (Sisters of Mercy, n.d a: online). Convents were also established in Iona (Pretoria), Mayfair (Fordsburg) and Rosebank (Johannesburg) (Sisters of Mercy, n.d b: online).

The area of Winterveldt, formerly used as cattle grazing in winter, was divided up in 1936, and sold as freehold agricultural holdings. People not able to obtain housing in other areas, settled in Winterveldt. With the independence of Bophutatswana in 1977, Winterveldt became part of a Tswana homeland (Sisters of Mercy, n.d c: online). Bophutatswana was a patchwork of five substantial pieces of land spread 250 miles to the north and west of Pretoria (Higgs and Evans, 2008: 510; Thompson, 2000: 186). People from Tswana ancestry lived in Ga-Rankuwa and Mabopane, while non-Setswana speakers (Ndebele, Zulu, Sotho, Venda and Shangaan) were grouped together in the Winterveldt, an informal dumping ground outside Pretoria (Higgs and Evans, 2008: 512). Severe discrimination existed towards non-Tswana speakers in the Bophutatswana homelands.

In 1977, The Mercy School in Mmakau was registered with the new Bophutatswana Department of Education, and continued to provide education for the surrounding areas. In August 1984, the Sisters opened an Adult Centre (an adult education Centre), in Winterveldt. During 1985, the Sisters bought a plot in the Winterveldt and started building the Mercy Centre (Higgs and Evans, 2008: 515). At Mercy Centre the focus is on community development. A pre-school, clinic, carpentry workshop, crafts center, food garden and a skills training center (computers, secretarial, backing, welding workshop, building project and paper making) were added. A new clinic (Mercy Clinic) was built in 1990, and the new clinic grew substantially. By 1997, staff at Mercy Clinic was treating 24,000 patients (Sisters of Mercy, n.d c: online). Among the many services offered was HIV & AIDS awareness. In 2003, Sr Christine Jacobs started the Kopano Lerato (Unity with love) club for orphans in their teens, to make a positive contribution to the lives of children affected by HIV (Sisters of Mercy, n.d d: online).

With the exception of three government clinics, healthcare in Winterveldt is provided by a network of six Catholic and Anglican Church clinics. These clinics provide curative services and HBC. With the availability of PEPFAR funding, the Mercy Clinic started an ART project in 2005, Hope for Life (Tallis and Harnmeijer, 2005: 12).

1.5.3. Tapologo, Rustenburg

Tsholofelo Community (Community of Hope) was founded in 1992 in Phokeng, near Rustenburg, in the then Bophutatswana homeland (Tsholofelo Community, 2008: online). The community works towards the development of communities, through guiding, training and supporting the people to help themselves.

The Community responded to the urgent need of people, who used to live next to the mission and who were relocated to Boitekong. Between 1993 and 1997, Sr Georgenia Boswell (registered nurse and Religious Sister) provided PHC from an informal structure in Boitekong, with the assistance of a local doctor (Dr van Schalkwyk), until the government started to provide services in the area (Dowling, 2008: interview). The Community's involvement with HBC started here when Sr Georgina trained twelve women to provide HBC in the area (Boswell, 2008: interview). From the beginning there was a strong emphasis that a registered nurse had to supervise HBC-workers and that ongoing training was essential. The fact that many of the original HBC-workers are still working with the project is testimony to the loyalty of the HBC-workers (Dowling, 2008: interview).

The next area Sr Georgina assisted was Freedom Park, an illegal squatter camp next to the Impala Mines. Among this community's greatest needs were, a clinic, a school for the children, an adult education center, a crèche and a skills development center. With the permission of the Royal Bafokeng, the project started in 1997. By May 1997, the PHC clinic opened, based in a pre-fabricated office. The same pattern was followed as in Boitekong. Sr Georgina trained six HBC-workers to assist the community. Within the first few months it was evident that many of the women and their babies were very ill and some died. The cause of these deaths was unknown, until a Botswana woman died on the floor of her shack while in labor. She had disclosed her HIV status, to her neighbors the day before (Boswell, 2006: 3). The community committee realized something had to be done. They started to realize the suffering HIV would cause. The role of the Church then was limited to care, as ART was not available (Dowling, 2008: interview). Tapologo (a place of peace and rest) was born.

In 1998, Impala Mines came to the rescue and assisted with infrastructure and funding for the training of 12 HBC-workers. By 2000, CRS had taken over the funding of the 12 HBC-workers in Freedom Park, while Impala Mines provided further support for 60 HBC-workers and three registered nurses to expand HBC to an additional five areas. By then, the project in Freedom Park had evolved to include five skills development projects, a local ward committee, a primary school, adult literacy classes, a crèche and a feeding scheme (Boswell, 2006: 6,7).

During the next few years, HBC services were extended to a further six areas. In February 2004, the project was delighted to hear that they had been selected as one of the projects that would receive PEPFAR funding through the SACBC to provide ART. Although they were working out of ship containers, providing sophisticated care with very few resources, their motto has always been that “you cannot allow a lack of infrastructure to stop you from doing something” (Boswell, 2008: interview).

The same year, Bishop Dowling’s (Bishop of the Diocese of Rustenburg, and co-founder of the SACBC AIDS Office) dream of providing patients with a place to die with dignity, came true when Tapologo opened an in-patient unit (IPU), with the financial support of Sun International (Dowling, 2008: interview).

Today, Tapologo is a thriving organization that provides HBC, ART and Orphan services, as well as hospice care to the people of Rustenburg (Dowling, 2008: interview).

1.5.4. HIV & AIDS Prevention Group, Bela-Bela

Since its inception in 1929, the Sisters of Charity, a Belgium order, have managed the St Vincent’s Hospital in Bela-Bela (then Warmbaths) (CATHCA, 2011: 68). The hospital was built one mile outside this small town’s city Centre. Four of the Sisters were sent for nurses training in Durban (St Vincent's, 2008: online). In 1935, Sr Henry (Lea Lapeire) became the first matron of the hospital. As the hospital expanded, more Belgian sisters and nurses-aides arrived. Staff shortages were still a problem, and the Sisters started training African nurses at the hospital. The first group passed their examination in 1940, and were awarded the Hospital Training Certificate. Later the SANC recognized St

Vincent’s as a training school for auxiliary nurses and hundreds of nurses received their training there (Gelfand, 1984: 236). In 1962, SANC recognized the hospital as a training school for enrolled nurses and midwives as well (St Vincent's, 2008: online).

Outreach work, into the township, was done by a Sister and two trainees on a weekly basis. The Emmanuel Clinic was later taken over by the Health Department of Hospital Services (Gelfand, 1984: 236, 237). St Vincent’s grew and expanded. Sixteen Sisters of Charity (all Belgian) worked at the hospital, aided by African staff and four physicians (Gelfand, 1984: 237).

After 1994, the local public hospital broadened their services to the Bela-Bela community and the demand for care from St Vincent’s changed. In 1997, St Vincent’s was upgraded and privatized as a non-profit organization, a casualty department and maternity unit were added and a retirement village was built nearby (CATHCA, 2011: 68; St Vincent's, 2008: online).

In 1996, Ms. Cecile Manhaeve (former Catholic Belgian volunteer) founded the HIV & AIDS Prevention Group (referred to as Bela-Bela in this document) in Bela-Bela, and started with extensive HIV & AIDS prevention and awareness campaigns. Between 1997 and 2007, the group tested 16,932 individuals (40% of whom were positive) (Ndjeka and Manhaeve, 2009). Their counselors were trained extensively and by 2001, HBC services were started. The group extended further and in 2003, orphan care and a wellness clinic were started (Ndjeka and Manhaeve, 2009: 10; Maponyane, Davidson and Dakovic, 2004). Ultimately, during 2004, the organization was able to extend their services, to include ART with PEPFAR funding.

A medical team, led by a specialist family physician, provided care to the patients. Sessional assistance from a dermatologist, ophthalmologist, internal medicine specialist, gynecologist and part-time medical practitioners was available with the full-time help of adherence counselors and an administrator (Ndjeka and Manhaeve, 2009: 5). In addition to providing patient care and support the organization also published several papers, spoke at international AIDS Conferences and provided training to other community-based organizations on the provision of HIV services (Ndjeka and Manhaeve, 2009: 35, 36).

1.5.5. Conclusion

Various parallels can be drawn between the history of Catholic healthcare throughout the "ebb and flow" of history. Chapter one highlight three "waves". With the **beginning** of Christianity, Catholic healthcare started with the Religious caring for the sick and poor. In the monasteries (for Religious men) and convents (for Religious women) the care of the sick was an important function. With the changing times of the plague and the Reformation, the Religious moved healthcare out of the monasteries and convents, Religious missionary bodies took nursing to the people. The provision of care was greatly influenced by changes in state control. The **second wave** described in the Chapter is the start of Catholic healthcare in South Africa. Religious Sisters arrived in South Africa in 1949 and started small dispensaries (clinics) and did home visits to the sick. Various Religious Orders worked throughout the country and established dispensaries and hospitals to provide healthcare where needed. Many of these institutions were in former homeland areas and provided valuable care to the sick, and training to the black populations around them. With state support the institutions flourished and expanded. In the 1970s, the changing environment in the country and changes in the state, affected the scene once again. The majority of the mission hospitals were taken over by the state or had to close due to the decrease in the number of Religious and funding for the institutions. The Religious continued their work with the sick and poor often, in very remote areas, through small clinics and HBC projects. The **third wave** can be seen at the dawn of the AIDS epidemic. Catholic healthcare was established in those communities severely affected by the epidemic. Work was started when the need arose, even before international funding, or the necessary political will realized. At the time of the study the Catholic Church's response to the AIDS epidemic was flourishing through the availability of PEPFAR funding.

From this Chapter it is evident that Catholic healthcare has made a lasting contribution to healthcare in South Africa. This will further be illustrated throughout the study.

CHAPTER 2: INTRODUCTION TO THE STUDY

HIV is the cause of AIDS (Cherepanov, 2000: 4). HIV depletes the CD4+ T-lymphocytes (hereafter referred to as CD4 cells) and progressively causes the destruction of lymph nodes. The resulting immunodeficiency eventually manifests itself as one or more of a large number of different diseases. Without treatment HIV progresses within years to severe immunodeficiency and death (Paredes, Sherer and Clotet, 2008: 422; World Health Organization, 2003: 43; Vlok, 1996: 600). From the time that the Centers for Disease Control and Prevention recognized it as a clinical entity in 1981, HIV has become a worldwide epidemic that has spread to all the continents within two decades (United Nations Program on HIV/AIDS and World Health Organization, 2005: 2; Centres for Disease Control, 1988: online).

2.1. The global epidemic

The HIV epidemic spread so extensively due to the long incubation period of AIDS, allowing widespread transmission before clinical cases were discovered. Rural-to-urban migration patterns, prostitution and a number of biological factors: high Viral loads (VLs), young age at first sexual intercourse, age differences between partners, high sexually transmitted infection (STI) rates and an absence of male circumcision played an aggravating role (Greenberg *et al*, 2008: 189). The epidemic caused destruction worldwide and by 2005 it was credited with the death of more than 25 million people, making AIDS one of the most destructive epidemics in recorded history (United Nations Program on HIV/AIDS and World Health Organization, 2005: 2; Talbot, 2000: online).

HIV prevalence remains high and the United Nations Program on HIV & AIDS (UNAIDS) (2010: 23) estimated that 33.3 million individuals worldwide were living with HIV at the end of 2009. These individuals will develop severe immunodeficiency and subsequent opportunistic infections (OIs), fueling other epidemics of global concern, TB being the most notable (World Health Organization, 2003: 43). TB has become the most common OI and the leading cause of AIDS-related deaths in the world (World Health Organization, 2007: 13).

Although HIV is a global epidemic, developing countries are most severely affected, with sub-Saharan Africa (SSA) bearing the brunt of the infection. In 2009 1.3 million (more than 72%) of the 1.8 million AIDS-related deaths worldwide occurred in SSA (United Nations Program on HIV/AIDS, 2010: 26). These are the countries that can least afford the extra burden of disease. The consequent death toll is not only a major health crisis but also a threat to economic development and social solidarity. It causes economic and social collapse while having a devastating impact on development: the epidemic is reversing development gains and population growth, destroying millions of lives, widening the gap between poor and rich, and undermining social and economic security (United Nations Program on HIV/AIDS and World Health Organization, 2005: 2; Pelser, Ngwena; Summerton, 2004: 276; Dorrington *et al*, 2001: 3).

In addition the millions of people with an increased need for medical care are crowding out patients suffering from seemingly less severe conditions than HIV & AIDS in hospitals in these countries (Tawfik and Kinoti, 2003: 22). Alternative mechanisms of care are therefore needed.

2.1.1. Care of HIV-infected patients

In 1986 the Committee on a National Strategy for AIDS in the United States introduced the idea that HIV-infected individuals need a diverse group of providers to care for them optimally. These providers should be based at hospitals (in-patient care), out-patient services and in communities (community-based care, including HBC) (Committee on a National Strategy for AIDS, 1986: 140-143). Hospital care was recommended for patients with serious OIs. The length of hospital stays would be minimized by providing out-patient and community-based services. These services would minimize the length of stay and therefore cut costs; yet patients would be provided with access to specialist care. Out-patient services would provide a patient with the opportunity to interact with professional HCWs in a clinical setting, after the initial hospital service. These hospital services are often in the form of a specialist HIV clinic with trained staff. Medical treatment that does not need hospitalization would be provided by nurses playing a pivotal role in providing education and counseling to patients. Community-based care and HBC, including basic nursing, assistance with daily activities and personal hygiene (provided by family members, neighbors and organizations) forms the basis of the care provided to the HIV-infected person. Community-based care is integrated with hospital and out-patient services. (Committee on a National Strategy for AIDS, 1986: 140-143). A very important component of HIV care is the provision of ART with a view to prolonging the HIV-infected individual's life.

2.1.2. Antiretroviral treatment

ART, as we know it, was introduced in 1996, fifteen years after AIDS was recognized, when researchers at the 11th International AIDS Conference in Vancouver announced successful treatment results for AIDS patients. Highly effective antiretroviral therapy (hereafter referred to as ART), a triple therapy regimen of antiretroviral agents was reported to reduce VL much more effectively than any one drug could and promised to prevent drug resistance that develops quickly with monotherapy (Schwartlander, Grubb and Perriens, 2006: 541).

The treatment can effectively control viral replication, but is unable to eradicate latent HIV which persists in the host, creating a reservoir of latent memory CD4 T-cells. This allows resurgence of viraemia when therapy is discontinued, necessitating life-long therapy (Wood, 2010: 531). At present HIV is still incurable, but the availability and correct management of ART could **change HIV-infection from a death sentence to a treatable chronic condition** with the life-expectancy of HIV-individuals now approaching that of people with other chronic diseases (Paredes, Sherer and Clotet, 2008: 422; Beck and Walensky, 2008: 56). The use of ART dramatically decreases rates of mortality and morbidity and improves quality of life (QOL) in HIV-infected populations where available (Egger, 2006: 817 and Mukherjee *et al*, 2003: 5; Goldie *et al*, n.d.: 1142).

ART quickly became an essential part of a comprehensive response to AIDS in rich countries, while it was seen as impossible or even irresponsible in developing countries. These countries lacked adequate healthcare infrastructure, resources, capacity and political will (Schwartlander, Grubb and Perriens, 2006: 541; Farmer *et al*, 2001: 404). However, the feasibility of delivering ART in resource-poor settings has been demonstrated in the last decade in several programs based in developing countries (Kim and Gilks, 2005: 2392; Coetzee *et al*, 2005: 889; Orrel *et al*, 2003: 1375; Farmer *et al*, 2001: 404). These programs reported a comparable decline in AIDS-related illness and death, achieving similar viral suppression and adherence rates as those in the developed world. This was possibly due to ART and diagnostics becoming more affordable through the implementation of access pricing for poor countries, increasing availability of generic formulations, development of fixed-dose combination therapies, and the availability of simplified guidelines for treatment.

The global community played a major role regarding commitments to the fight against HIV by international agencies. These commitments included the World Health Organization's "3 by 5" program (to provide 3 million HIV-infected patients with ART by 2005), unprecedented funding by the Global Fund to fight AIDS, TB and Malaria (Global Fund), PEPFAR and the World Bank (Egger, 2006: 817; Schwartlander, Grubb and Perriens, 2006: 541 – 543; World Health Organization, 2006b: 6; Kim and Gilks, 2005: 2395).

These possibilities do not change the fate of millions of infected individuals who do not have access to treatment. Most countries with a high prevalence of infection cannot provide the lifesaving treatment to all as the number of people in need of treatment still exceeds the capacity to provide it (Kim and Gilks, 2005: 2394). In 2006, Schwartlander, Grubb and Perriens, (2006: 541) concluded that although the progress on access to ART might have no precedent in global health (moving from scientific breakthroughs to a commitment to achieve universal access to treatment in less than a decade) there are still millions dying from AIDS every year. There is thus a great need to ensure universal access to ART for all.

2.1.3. Universal access

Regardless of the possibilities available, the aim of the “3 by 5” program, namely to treat 3 million people in low- to middle-income countries by the end of 2005, failed (only 1.3 million were reached). Inadequate drug supply management, insufficient human resources and trained medical professionals, and a lack of evaluation contributed to the failure (Wagner, Ryan and Taylor, 2007: 871). Recognizing the urgency to increase access to those who need ART, leaders of the G8 countries agreed to “work with the World Health Organization, UNAIDS and other international bodies to develop and implement a package for HIV prevention, treatment and care, with the aim of universal access to treatment for all those who need it by 2010”. The goal to universal access was endorsed by United Nations member states in September 2005 (World Health Organization, 2006: 5). At the time an estimated 6.8 million people globally needed ART to avoid AIDS-related death; only a quarter (1.65 million) of those were on ART (World Health Organization, 2006b: 12).

The key challenges identified at the time were: weak drug procurement and supply management systems, poor laboratory infrastructure and severe human resource shortages. With these challenges in mind it was important to identify priorities to scale up treatment and care, including updating national treatment guidelines to include the most appropriate recommendations for first- and second-line regimens; to develop improved drug formulations for adults and children; to develop models of delivery that ensure equity; to maintain continuous supplies of drug and diagnostics; and to develop drug formulations for adults and children (World Health Organization, 2007: 13, 14). When lifelong treatment has to be provided an additional challenge is the implementation of effective health policies and systems of care and prevention that will prove to be durable and sustainable (Paredes, Sherer and Clotet, 2008: 444)

The World Health Organization recognized that public health agencies cannot achieve universal access on their own in Africa (World Health Organization, 2007: 1). Efforts are needed to encourage greater collaboration between public health agencies and faith-based organizations (FBOs), if progress is to be made towards the goal by 2010 (World Health Organization, 2007: 1; Ecumenucal Advocacy Alliance, 2006: 3).

This study will examine the collaboration between the South African Government (SAG) and one of the largest FBOs providing healthcare in South Africa. Working in South Africa has its own challenges though.

2.1.4. South Africa

HIV spread rapidly through the South African population after the first cases were described in 1982. In the decade between 1990 and 2000, HIV sero-prevalence among antenatal clinic attendees increased “explosively” from 0.8% to 24.5%. The South African epidemic grew to the largest in the world. The 5.6 million infected individuals contribute to 17% of the HIV burden globally. At present the epidemic is a generalized, mature, subtype C epidemic where the prevalence has stabilized with high rates of morbidity and mortality. Prevalence varies by age, gender and geographic area (Abdool Karim and Baxter, 2010: 43; Gouws and Abdool Karim, 2010: 55, 61).

The response to HIV was plagued by denial where political agendas obscured science (Wood and Martin, 2008: 276). At first, the apartheid government ignored the disease. After the birth of democracy the Mandela government had the mammoth task of establishing a non-racial democracy, and the disease had time to establish itself within South African communities. The second democratically elected president, Mbeki, and his cabinet openly denied that HIV caused AIDS and supported alternative medicine and diet solutions, compromising the roll-out of ART that started under his government (Abdool Karim and Baxter, 2010: 43). Insufficient political will was demonstrated until 2009 under the Zuma government (Abdool Karim and Baxter, 2010: 43).

Activism played a major role in promoting the access to ART as South Africa lacked political leadership at the time (Wood and Martin, 2008: 278). In 1992, the National AIDS Coordinating Committee of South Africa was launched with a mandate to develop a national strategy for addressing HIV & AIDS. Cabinet endorsed the strategy in 1994. In 1999, through a consultative process with stakeholders, a National Strategic Plan (NSP) (NSP 2000-2005) was developed (South Africa , 2007: 17). The NSP 2000-2005 (South Africa , 2007) mentioned only limited use of antiretroviral drugs for post-exposure prophylaxis and prevention of mother-to-child transmission (PMTCT) of HIV (South Africa, 2000: 20, 25). No immediate action was taken and civil society had to get a constitutional court ruling to force the SAG to start providing Nevirapine to pregnant women. The PMTCT program scaled up in 2004 to just over half of the pregnant women in the country (South Africa, 2006: 5). National treatment guidelines allowing for triple therapy were published in 2003, containing two standardized ART regimens (South Africa, National Department of Health, 2003). In April 2004, South Africa launched an ART program through the public health system. Prior to this, ART was provided through the private sector and a few local initiatives (Schneider *et al*, 2010: 1). The public rollout was guided by the Operational Plan for Comprehensive HIV & AIDS Care, Management and Treatment for South Africa (hereafter referred to as the *Comprehensive Plan*) (South Africa, National Department of Health, 2003).

The South African ART roll-out took off and by 2006 approximately 230,000 HIV-infected individuals were receiving ART. The worrying fact was, however, that in the same year a further 540,000 individuals were sick with AIDS but not receiving ART. Without access to ART 950 lives were lost per day (South Africa , 2007: 39) . It was therefore the goal of the NSP 2007 - 2011 (South Africa , 2007) to reduce the rate of new HIV-infections by 50% by 2011; and to reduce the impact of HIV & AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all HIV-positive people and their families by 2011 (South Africa , 2007: 10). Reaching universal access would increase survival rates by as much as 64% (Walensky *et al*, 2009: 1).

The scale-up has continued and by 2009 South Africa had the largest ART program in the world, nearing 1 million on treatment. This achievement amounts to 56% of the people in need of ART having access to ART (United Nations Program on HIV/AIDS, 2010: 29). The target of 80% coverage by 2011 is thus still eluding South Africans. The public sector cannot achieve these goals in isolation.

At the third Southern African AIDS Conference in Durban, Mark Heywood of the AIDS Law Project emphasized that the implementation of the NSP 2007 – 2011 (South Africa , 2007) and the necessary expansion of access will depend on a broad social mobilization to ensure that all levels of government, civil society and the business community share the task of achieving the ambitious targets (Alcorn, 2007: online). Non-governmental Organizations (NGOs) have an important role to play in collaboration with the public sector if access to ART is to be expanded.

2.1.5. Non-governmental Organizations

Non-government Organizations (NGOs) have pioneered innovative strategies to respond to HIV & AIDS since the beginning of the epidemic. These strategies have influenced the main ideas found within the HIV & AIDS sphere. This is due to the inherent advantages of the way NGOs tend to operate, as well as the fact that governments were initially reluctant to respond to HIV & AIDS (De Jong, 2003: 7).

In many countries the response to HIV & AIDS is dependent on these external health initiatives that can by-pass the systemic deficiencies of the public healthcare systems by creating “vertical programs” (McCoy, 2006: 3). A call has gone out for a new strategy and commitment to relationships and responsibilities that allow collaborative coherent governance and management of healthcare systems. Building relationships between NGOs and the public sector will improve the fragmented, incoherent and disorganized state of some public healthcare systems (McCoy, 2006: 3, 9). The contributions made by NGOs are very important. This study focuses on the contributions of one faith-based NGO.

2.1.6. Faith-based Organizations

FBOs (also known as Religious entities) own an estimated 30% to 70% of the health infrastructure in Africa. Apart from owning a substantial portion of health infrastructure they have been shown to have other critical, but less tangible, assets (African Religious Health Assets Program, 2006: 7). **These assets include**

extensive volunteer networks, experience lay-professionals, and infrastructure in even the most remote locations. They also provide systems of community support, "voice," advocacy, trust, consolation, and hope. Furthermore, they have been part of local communities' right from the beginning of the crisis, at the very forefront of caring for those affected by HIV & AIDS. These characteristics put them in an excellent position to mobilize communities to respond to the basic needs of people affected by the disease, and indeed to pioneer much of the community-based work (Chikwendu, 2004: 311). Therefore the World Health Organization identified FBOs as key partners in the effort to achieve universal access (African Religious Health Assets Program, 2006: 6).

The rationale for FBO engagement in universal access lies in the understanding of the term. Universal implies a sense of equality in access to prevention, care, treatment and support. The notion of access is intimately tied to the concepts of availability, affordability and acceptability. From an African perspective, all of these concepts can be related to the strengths and capabilities of FBOs (African Religious Health Assets Program, 2006: 19). FBOs are substantial partners in delivery of care, treatment and support in the most rural areas and in the poorest neighborhoods of the world (Ecumenucal Advocacy Alliance, 2006: 1). FBOs have the experience and capacity to address the epidemic through sustainable programs by not only providing services, but also by addressing the spiritual needs of people affected by the disease (World Council of Churches, 2001: 2). It is argued that health, religion and cultural norms and values define the health-seeking strategies of many Africans. The failure of health policy makers to understand the overarching influence of religion and the important role of FBOs in HIV treatment and care could seriously undermine efforts to scale up health services (World Health Organization, 2007: 1). An important religious entity rendering healthcare is the Catholic Church.

2.1.7. The Catholic Church

The Catholic Church (hereafter referred to as the Church) is the world's largest Christian denomination (Ecumenucal Advocacy Alliance, 2006: 48). It is a vibrant, dynamic community of faith providing spiritual and social renewal within a complex and multi-layered network of institutions spanning the globe. In Africa alone by 2001 the Church had more than 10,000 parishes and 75,000 mission stations (Chikwendu, 2004: 311). In Southern Africa the Church has a strong presence. The SACBC covers twenty nine dioceses in South Africa, Swaziland and Botswana (Munro, 2006a: online).

The Church has a long history of providing healthcare. Before the Reformation, in the 16th century, all nursing of the poor was done by Catholic Religious Orders which devoted their lives to charitable acts (Searle, 1965: 134). In South Africa the Church's history is interwoven with the history of nursing. From the time the first women belonging to a Religious Order arrived in South Africa on 3 December 1849 the sisters started establishing dispensaries (clinics) and hospitals as part of the missionary effort (Searle, 1965: 89, 153). The work of the Church continued and by 1954, there were 48 Catholic hospitals and 178 clinics in South Africa (Salesian Institute, 1954: 2). Catholic nurses and health professionals, mainly Religious, cared for a large part of the population (Smith , n.d.: 1). Christopher Benn (African Religious Health Assets Program, 2006: 19) estimated that the Church provided 25% of all HIV & AIDS care (including HBC and support to orphans) in the early 2000s.

The Church's response to the HIV epidemic was a natural result of its long history of caring for the sick. The Catholic Network includes hundreds of service projects which reach into every district in the country, providing a full range of services, including health education, HBC to the sick, hospices, orphan care, medical care, and spiritual and psychosocial support (Stark, 2007: 1). The

Church’s response to HIV in Southern Africa is coordinated by the SACBC AIDS Office in Pretoria (Munro, 2006a: 1).

Since being established in 1999, the SACBC AIDS Office has assisted diocesan responses to HIV & AIDS relating to prevention, care and treatment. The backbone of the Church’s response from the beginning has been care and support projects (Munro, 2006a: online). As part of the response to HIV & AIDS, the SACBC AIDS Office coordinates more than fifty HBC projects. In 2005 the AIDS Office (through a grant managed by CRS) selected twenty of these ART projects to provide ART in resource-limited settings. Funding for the program was provided by PEPFAR. At the end of the third year of the five-year program, about 10,000 people were receiving ART and at least 30,000 people were receiving HIV care at twenty projects throughout the country, mostly in under-serviced rural areas (Stark, 2007: 1). The reach and size of the program makes the Church a noteworthy contributor in the HIV & AIDS response in South Africa. This is a point to be noted in the public sphere where there are many opinions, not all of them positive and helpful, about the role of the Church (Munro, 2007: 80).

2.2. Problem statement and rationale

In 2006 AIDS-related illnesses killed nearly 1,000 South Africans a day, regardless of the availability of ART in selected facilities in the country (Abdool Karim and Abdool Karim, 2010: 585; South Africa, 2007: 39). This high death toll can be attributed to insufficient access to ART.

The lack of access is a global concern. By 2006 the World Health Organization had declared the failure to deliver ART to those who need it as a global health emergency (World Health Organization, 2006b: 150). Urgent scale-up of programs and better cooperation between service providers are needed if universal access is to be reached (Kim and Gilks, 2005: 2394; De Jong, 2003: 12-13; Family Health International, 2003). One of the priorities the World Health Organization identified to scale up treatment and care was to develop models of service delivery that ensure access to treatment for all (World Health Organization, 2007: 13, 14). Furthermore, Calmy *et al* (2004: 2354) highlighted that successful Western approaches could not be replicated if large numbers of patients were to be reached in developing countries. Models of care (MOC) in the developing world need to take into account limited human resources, limited laboratory services, limited availability of drugs and lack of access to monitoring tools. A 'model of care' is a multifaceted concept, which broadly defines the way health services are delivered. It can therefore be applied to health services delivered in a unit, division or a whole district (Queensland Health, 2000: 4).

Several HIV treatment programs have been successfully implemented in the developing world, with similar viral suppression and adherence rates as those in the developed world (Coetzee *et al*, 2005: 889; Kim and Gilks, 2005: 2392; Orrel *et al*, 2003: 1375; Farmer *et al*, 2001: 404). Describing these existing MOC can be a used: as a standard to develop models of service delivery; to discuss ways to achieve universal access to ART; to influence policies and therefore future program planning (Nelson Mandela Foundation, 2006: i). Coetzee *et al* (2005: 894) describe the need to explore program design choices that impact on clinical outcomes in developing countries as urgent. A limited number of studies have been undertaken to record successful programs.

In 2006 the University of Cape Town produced a research report on MOC conducted by the School of Public Health and Family Medicine at the University (Pienaar *et al*, 2006). Five projects in the Western Cape were evaluated to describe major features and current approaches to the provision of ART. Four MOC in the Free State were investigated in collaboration with the Centre for Health Systems Research and Development (CHSR&D) at the University of the

Free State (UFS) (Engelbrecht *et al*, 2008). In a separate process, but using similar methodologies, four projects were evaluated in Gauteng (Schneider et al, 2008a). In 2008 the results of these three studies were combined in a report, comparing the MOC from the three provinces (Schneider et al, 2008b).

Considering the substantial contribution NGOs, and in particular FBOs, have made in the delivery of HIV-related services there is a definite need to investigate MOC in this sector. Therefore the researcher will attempt to describe, analyze and compare different MOC for ART delivery in an established ART program managed by an FBO. The SACBC program was chosen as it is a well-established program with a vast reach across South Africa serving nearly 10,000 HIV-infected individuals on ART.

2.3. Aims of the study

The intent of this single case-study is to describe, analyze and compare four different MOC for ART delivery as embedded units of analysis in an FBO.

2.3.1. Objectives

The objectives of the study are to describe, analyze and compare MOC for ART delivery, looking at:

- ✓ The historical background of the projects.
- ✓ The accessibility of the different models including the infrastructure available.
- ✓ The profile of patients who have accessed care.
- ✓ The continuum of care provided:
    - o The range of services provided

  - The human resources available (including the identification of the role of the registered nurse in providing ART)
- ✓ The patient outcomes.
- ✓ Aspects that could inform future service planning, policy development and healthcare.

2.4. Philosophical approach and research paradigm

Two philosophical approaches have influenced the study, namely the philosophical approach of the Church and that of the researcher. The philosophical approaches of the Church influence the work ethics of the Church and its motivation to care and support HIV-infected individuals. The researcher's own religious view and involvement with the program may also influence her interpretation of the findings.

2.4.1. The Catholic Church

The response of the Catholic Church is founded in the principles (social teachings) that guide the Church (Munyaradzi, 2007: online). Munro (head of the SACBC AIDS Office) summarized these as follow: "It is, I think, the faith commitment of people that defines their response to AIDS as somewhat and somehow different from the response of people who are employed to do a job in the same sphere" (Munro, 2006a: 1). De Waal (2005: 25) concluded that faith plays an important role in the lives of many of the SACBC program staff. Personal belief systems drive and sustain individuals and teams, without dominating the treatment and care projects. The key guiding principles of the Church's social teaching according to the Office for Social Justice, Archdiocese of St Paul and Minneapolis (2006: online) are:

- ✓ **Dignity and equality of the human person**

All of humanity has been created in the image of God and possesses a basic dignity and equality that comes directly from our creation and not from any action on our own part.

- ✓ **Rights and responsibilities**

Every person has basic rights and responsibilities that flow from our human dignity and that belong to us as humans, regardless of any social or political structures. The rights are numerous and include those things that make life truly human. Corresponding to our rights are duties and responsibilities to respect the rights of others and to work for the common good of all.

- ✓ **Social nature of humanity**

All of us are social by nature and are called to live in community with others; our full human potential is not realized in solitude, but in community with others. How we organize our families, societies and communities directly affects human dignity and our ability to achieve our full human potential.

- ✓ **The common good**

In order for all of us to have an opportunity to grow and develop fully, a certain social fabric must exist within society. This is the common good. Numerous social conditions, economic, political, material and cultural impact on our ability to realize our human dignity and reach our full potential.

- ✓ **Subsidiarity**

A higher level of government (or organization) should not perform any function or duty that can be handled more effectively at a lower level by people who are closer to the problem and have a better understanding of the issue.

- ✓ **Solidarity**

We are all part of one human family (whatever our national, racial, religious, economic or ideological differences) and in an increasingly interconnected world, loving our neighbor has global dimensions.

- ✓ **Option for the poor**

In every economic, political and social decision, a weighted concern must be given to the needs of the poorest and most vulnerable. When we do this we strengthen the entire community, because the powerlessness of any member wounds the rest of society.

- ✓ **Stewardship**

There is an inherent integrity to all of creation and it requires careful stewardship of all our resources, ensuring that we use and distribute them justly and equitably, as well as planning for future generations.

2.4.2. The researcher

Although the researcher does not belong to the Catholic Church, she identifies with Christianity and her religious believes and involvement with the Catholic Church may influence her interpretation of the research findings. The researcher believes that as followers of Jesus Christ we are called to care for the sick. In the words of Matthew 25: 40 "The King will reply, “I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me" (New International Version, 1984: 40).

The researcher is employed by CRS, the lead agency funding the SACBC ART program. CRS provides technical support to the SACBC ART projects. The researcher is appointed as a project manager, responsible for managing the monitoring and evaluation functions of the program. The researcher thus has access to the SACBC projects, the staff and the patient data as part of performing her responsibilities. The projects are accustomed to providing information to the researcher and have been doing so for the past six years.

It might be argued that these conditions provide the researcher with a unique insider view. Burns and Grove (2005: 213) state that the nature of relationships between researcher and the individuals being studied has an impact on the data collection and interpretation. Thus an important concern in designing a study is to identify possible sources of bias and to eliminate or avoid them. If they cannot be avoided, the study must be designed to control these sources of bias. Bias will be controlled by employing triangulation techniques as well as ensuring validity and reliability.

2.5. Research design

The study will be conducted using case-study methodology. An embedded single case design will be used to investigate a single case with more than one unit of analysis (Yin, 2003: 42; Patton, 2002: 447). Concurrent, mixed methods are utilized where both qualitative and quantitative methods will be used to collect data from patients, home-based- and HCWs. By describing, analyzing and comparing the four MOC for ART delivery, their patient profiles, access and continuum of care and project outcomes will be determined in order to provide information that can influence future service planning and policy development.

Data will be collected through various techniques and from different sources such as structured interviews, semi-structured interviews, nominal groups and file audits. This will allow the researcher to validate and cross-check findings using triangulation to ensure their validity and therefore influence the rigor of the study.

2.5.1. Rigor

Burns and Grove (2005:55) state that "scientific rigor is valued because it is associated with the worth of research outcomes", and studies are critiqued as a means of judging rigor.

The study will be conducted in three phases: preparation, data collection, and the conclusion. Discussions of the implementation of the three phases will follow.

2.6. Phase I - Preparation

Before the study can commence the researcher will do extensive preparation. The preparation will involve developing the research proposal, refining data colection tools, obtaining ethical approval, obtaining permission to do the study, conducting a pilot study, and preparing for the next phase (doing fieldwork) of the study.

2.6.1. Proposal development

The researcher was part of the MOC study that was conducted in the Free State (Engelbrecht *et al*, 2008) (see section 2.2). The proposal will be developed in cooperation with the CHSR&D at the UFS. The Department of Biostatistics from the UFS will assist with the sampling of the number of patients who have to be interviewed while case selection will be done by the researcher using stratified sampling.

2.6.2. Case selection

Sampling is a process of selecting elements for participation in a study from the target population identified (Burns and Grove, 2005: 34, 342). The researcher will select four projects (cases) from a list of ART projects managed by the SACBC. This will be done by stratifying the projects into four types of MOC and purposely selecting one project in every MOC. Studying these cases will enable the researcher to study information-rich cases making an in depth study possible (Patton, 2002: 230).

After obtaining the necessary permission from the research committee within the School of Nursing, the researcher will apply for ethics approval from the ethics committee of the Faculty of Health Sciences at the UFS.

2.6.3. Ethics approval

The design and methodology of the study will be submitted to the ethics committee for Health Sciences at the UFS for evaluation and approval. After receiving ethics approval from the committee the researcher will seek approval to conduct the study from the relevant stakeholders.

2.6.4. Ask permission to conduct research

Permission to conduct research will be obtained from the SACBC, the pilot project and the four projects and any relevant provincial department of health (DoH). After the necessary approval is obtained a pilot study will be conducted.

2.6.5. Pilot study

The MOC study that was done by the CHSR&D will be seen as a pilot case-study. The researcher conducted the research at the Catholic ART project in Botshabelo as part of the MOC study done by the CHSR&D (Engelbrecht *et al*, 2008). The tools used by the CHSR&D will be refined and any changes made will be piloted again at the project. After the pilot study the researcher will prepare to do fieldwork.

2.6.6. Preparation to do fieldwork

An assessment of the facilities, time schedules and arrangements to visit the projects will be made. The language capabilities of participants at the projects will be identified and taken into account. Fieldworkers will be recruited and trained in interviewing skills. After these preparations the fieldwork will commence.

2.7. Phase II - Data collection

Data collection is the precise, systematic gathering of information relevant to the research purpose and the specific objectives or questions of a study (Burns and Grove, 2005: 42). The key strength of the case-study method lies in the use of various data collection techniques as is typical of a mixed method design (Yin, 2003: 97 and Patton, 2002: 297 and Soy, 1997: online). The researcher and a group of trained fieldworkers will visit each project for 14 – 20 days at a time. Data will be collected through various techniques: structured and semi-structured interviews, file audits and nominal groups.

During the data collection phase the research participants will be protected. The researcher will follow prescribed ethical principles.

2.7.1. Ethics

Researchers have an ethical obligation to their study population (Berg, 2007: 53). Three principles relevant to conducting ethical research will be adhered to: respect for persons, beneficence, and justice (Burns and Grove, 2005: 735). The participants will be protected by ensuring them full information of the purpose of the study and the potential risks in participation, and reassuring them that they will not be penalized if they do not participate. Informed consent will be obtained from all participants and measures will be taken to ensure confidentiality of their information.

These ethical precautions will be followed when collecting data through all the different data collection techniques. Patients on ART at the facilities will be interviewed using a structured interview.

2.7.2. Structured interviews

There are three major categories of interviews: the structured, informal or semi-structured interviews. These interview types have different degrees of presentation structure (Berg, 2007: 92). Fieldworkers will conduct structured interviews with ART patients at each project. The fieldworkers will have to adhere strictly to an interview schedule. The interview schedules will be developed in cooperation with staff at the CHSR&D at the UFS (see section 3.2.1). The questionnaire used in the MOC study (Engelbrecht *et al*, 2008) conducted by the CHSR&D will be refined. Sampling will be done by the Department of Biostatistics at the UFS based on a list of patients numbers provided to them by the researcher. The data analysis will also be done by the Department of Biostatistics. Reliability and validity of the instrument will be ensured by testing the instrument before use, training fieldworkers on how to use the schedule and by validating data in the field for completeness.

The patient files of all the respondents who participate in the structured interviews will be audited.

2.7.3. File audits

Clinical data related to the respondent’s clinical outcome will be collected from the respondent’s patient file. Collecting documentary information is important in case-study methodology (Yin, 2003: 85). The file audit schedule will be developed based on program evaluation data used by Professor Robin Wood. Professor Wood conducts annual program evaluations on the SACBC data. All files of the respondents who participated in the structured interviews will be audited. The data analysis will also be done by the Department of Biostatistics.

Project managers and HCWs will be interviewed using semi-structured interviews.

2.7.4. Semi-structured interviews

Semi-structured interviews are interviews organized around areas of particular interest that allow considerable flexibility (De Vos *et al*, 2005: 292, 296). The researcher will have a set of predetermined questions on an interview schedule. The two semi-structured interview schedules will be developed in conjunction with staff at the CHSR&D at the UFS. Staff at the facilities will be interviewed regarding the project and their work experience. Interviews will be done to a point of saturation. Data analysis will be done by the researcher. The information will be tabulated, summarized and reported in the research report.

The staff interviewed using semi-structured interviews will all be professional staff. Data will be collected from the community-based HBC-workers by using the nominal group technique (NGT).

2.7.5. Nominal groups

The NGT is a structured variation of small-group discussion methods (De Long, 2004: online). HBC-workers will be asked the question "*What do you need to be a good HBC-worker*". The groups will be held to the point of saturation. The size of the group will be between seven and nine respondents with a maximum size of about 12 people (Delbecq, Van de Ven and Gustafson, 1975: online). Groups will be facilitated by a trained fieldworker and the researcher. The seven steps suggested by Delbecq, Van de Ven and Gustafson (1975: online) will be used. The initial data analysis will be done by the group whereafter the researcher will analyse the multiple-group data based on the work by Van Breda (2005: 4-11). Once the fieldwork is conducted the final conclusion phase will begin. Critique

2.8. Phase III - Conclusion

In the final phase of the research the research report will be written after the data has been entered and analyzed. Data entry and analysis for the structured interviews and the file audits will be done by the Department of Biostatistics at the UFS (see section 3.3.1.3). The rest of the data will be analyzed by the researcher. The findings of the study will be discussed in the research report.

2.9. Chapter outline

The report will be divided into eight chapters.

Chapter 1 is a brief historical introduction to the role the Catholic Church played in healthcare in South Africa leading up to the provision of ART.

Chapter 2 is the introduction to the study and discusses the three phases in which the study will be conducted.

Chapter 3 describes the methodology used to conduct the study. The different data collection methods will be discussed.

Chapter 4 describes the access to care in the different models. Attention will be given to the infrastructure at the facilities and the patients who were served by the MOC.

Chapter 5 focuses on the continuum of care provided to patients by the different MOC. Attention will be given to the services provided.

Chapter 6 addresses a crucial element of ART delivery: human resources. Special attention will be given to the role of the registered nurse, the role task-shifting plays and the deployment of HBC-workers.

Chapter 7 summarizes the findings and conclusions made. The researcher will provide recommendations for future ART provision.

The Bibliography will provide an extensive list of literature sources cited in the study.

CHAPTER 3: METHODOLOGY

Chapter Three sets out to describe the methodology used in the study. The research design and the three phases used in the study and the data collection methods are described in detail.

3.1. Research design

The study was conducted using case-study methodology. Case-study methods involve intensive exploration of a particular person, group or organization to allow insight into how the subject of intervention operates, by the systematic gathering of data (Berg, 2004: 251). The method is well known and established (Ivankova, Creswell and Clark, 2007: 268). Yin (2003: 13) further defines a case-study as an "empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident." In the study the phenomenon cannot be studied outside the context in which it occurs (Babbie and Mouton, 1998: 281). The different MOC were studied within the context of the FBO as the faith-dimension significantly influenced the care provided (De Waal, 2005: 25).

An advantage of the case-study approach is that it allows for the identification of factors that are constant between or vary among units by looking for patterns across cases (Neuman, 2006: 40, 438). Different MOC can therefore be identified and compared. The design further allows for the comparison of single cases or multiple cases. Within the single case-study the cases can be all-inclusive or embedded (layered) (Yin, 2003: 39; Patton, 2002: 447).

3.1.1. Embedded single case design

An embedded single-case was used to investigate a single case with more than one unit of analysis. The single case (SACBC program) was described with subunits (different MOC) embedded within the case-study (Yin, 2003: 42; Patton, 2002: 447). The analysis began with the embedded individual case studies. Thereafter a cross-case pattern analysis could be done to form the data for the program case-study. This kind of layering recognizes that you can build larger case units out of smaller ones. It is therefore important to collect data on the lowest possible level of analysis in order to do justice to each individual case (Patton, 2002: 449).

The case-study method was not used as a data-gathering technique but as a methodological approach that incorporates a number of both qualitative and quantitative data-gathering measures (Burns and Grove, 2005: 238; Yin, 2003: 59; Babbie and Mouton, 1998: 281). The approach is called the mixed methods approach.

3.1.2. Mixed method approach

The mixed methods approach is one in which the researcher tends to base knowledge claims on pragmatic grounds (e.g., consequence-orientated, problem-centered, and diverse). It employs strategies of inquiry that involve collecting data either simultaneously or sequentially to best understand research problems. In the study, data collection involved the simultaneous gathering of both numeric information as well as text information. The final dataset could therefore represent both qualitative and quantitative information in order to best understand the phenomenon under study (Ivankova, Creswell and Clark, 2007: 266; Creswell, 2003: 19, 20). The datasets were gathered simultaneously as the researcher had access to the different sources simultaneously. The approach influenced the rigor of the study.

3.1.3. Rigor

Rigor is defined differently for qualitative and quantitative research because the desired outcomes are different. In quantitative research, rigor is reflected in narrowness, conciseness and objectivity and leads to rigid adherence to research designs and precise statistical analyses. In qualitative research, rigor is associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data in the subjective theory development phase. Evaluation of the rigor of a qualitative study is based, in part, on the logic of the emerging theory and the clarity with which it sheds light on the studied phenomenon. The reliability and validity of research findings are of great importance in all studies. (Brink, 2001: 124). In this study attention was given to enhancing validity, reliability and trustworthiness.

3.1.3.1. Validity

Study validity is a measure of the truth or accuracy of a claim and is an important concern throughout the research process (Burns and Grove, 2005: 214, 755). Within the mixed method approach triangulation or cross checking of data occurs frequently. Comparing measures from different sources (triangulation) enhances the validity of the study (Burns and Grove, 2005: 383).

Triangulation occurs when multiple referents are used to draw conclusions about what constitutes the truth (Polit, Beck and Hungler, 1995: 313). Authors have described various types of triangulation. The researcher made use of methodological and data triangulation.

- ✓ **Methodological triangulation** was employed as qualitative and quantitative methods (between-method triangulation) were used to collect data about the same phenomenon to enhance the validity of the findings

(Burns and Grove, 2005: 226; Polit and Beck, 2004: 723; Patton, 2002: 559). The datasets were collected simultaneously (concurrent triangulation procedures), enabling the researcher to confirm, cross validate and substantiate findings.

- ✓ In **data triangulation** multiple data-gathering methods offset the weakness inherent within one method with the strengths of the other method (De Vos *et al,* 2005: 314; Creswell, 2003: 16, 217). Burns and Grove (2005: 225) explain that data triangulation involves the collection of data from multiple sources for the same study: the data all have the same foci with the intent to obtain diverse views of the phenomenon under study for purposes of validation. The results from the different data-gathering methods, e.g. structured interviews, file audits, semi-structured interviews and nominal groups were integrated during the conclusion phase.

Different types of validity were addressed during the lifetime of the study. These included construct validity, concept validity and external validity.

With **construct validity** the researcher must establish the correct operational measures to ensure the constructs (concepts at very high levels of abstraction) that are meant to be measured, are measured (Babbie, 2007: 147; Burns and Grove, 2005: 731; Yin, 2003: 34). This will mean that results are stable across multiple measures of a concept (Burns and Grove, 2005: 227). In the study construct validity was enhanced by using multiple sources of evidence, establishing a chain of evidence and by key informants reviewing a draft copy of the report (Soy, 1997: online).

Content validity is concerned with the degree to which an instrument has an appropriate sample of items for the construct being measeured (Polit, Beck and Hungler, 1995: 423). The instrument needs to measure what it is supposed to measure (also called face validity). Content validity was enhanced by basing the data-gathering tools on well tested tools used in previous studies such as Engelbrecht *et al* (2008). The tools were further refined during the pilot study to enhance the validity. The file audit schedule was based on annual program evaluations done by an experienced researcher in the field of HIV, based at the Desmond Tutu HIV Research Centre in the Western Cape.

External validity is enhanced by establishing the domain to which the study's findings can be generalized beyond the sample used in the study (Burns and Grove, 2005: 736; Yin, 2003: 34). External validity is also refered to as population validity. Population validity refers to the degree to which the findings obtained for a sample may be generalized to the total population of the research. Population validity was enhanced by using techniques such as cross-case examination and within-case examination along with a literature review (using theory) in the conclusion phase (Soy, 1997: online). Large sample sizes were also used to enhance this particular type of validity.

3.1.3.2. Reliability

The reliability of a study is represented by the consistency of the measures obtained and the fact that it can be repeated, with the same results and witness to the stability, accuracy, and precision of measurement (Burns and Grove, 2005: 749; Yin, 2003: 34; Soy, 1997: online). It refers to the degree the instrument will yield consistent results over time (Brink, 2001: 171). Reliability was promoted by:

- ✓ Translating (and back-translating) the structured interview schedule (administered to ART patients) and the nominal group question (conducted with HBC-workers) into Zulu and Tswana to ensure the participants fully understood what was asked of them.

- ✓ Refining tools used in a large study by Engelbrecht *et al,* (2008). The refined tools were piloted at another Catholic facilty to allow the researcher to determine the reliability of the measuring instruments when used in the population (Talbot, 1995: 74).
- ✓ Training fieldworkers in interview techniques and doing role-play to ensure the fieldworkers knew how to conduct the structured interviews.
- ✓ Establishing the competency of the researcher to conduct group work. The researcher underwent evaluation from an experienced senior lecturer at the UFS to establish her competency to conduct group work (NGT). The lecturer declared the researcher's skills were sufficient.
- ✓ Using a competent facilitator to conduct the nominal groups: nominal groups were conducted by the researcher or a trained facilitator. The facilitator holds a Bachelor degree in Psychology, is fluent in Zulu, Tswana, South Sotho and English. She was trained by the researcher and did two sessions in the presence of the researcher to establish her competency.
- ✓ Using the designated data-gathering tools (standardized interview schedules, file audit schedules, semi-structured interview schedules and nominal group questions) systematically and properly in collecting the evidence.

To meaningfully apply rigor for the qualitative data analysis, trustworthiness was considered important in the evaluation of the data quality (Nieuwenhuis, 2007: 113; Polit and Beck, 2004: 430).

3.1.3.3. Trustworthiness

The criteria that needed to be met to enhance trustworthiness were: credibility, dependability, confirmability and transferability (Polit and Beck, 2004: 430; Talbot, 1995: 487).

Credibility ensures that the researcher has developed plausible interpretations and conclusions (Talbot, 1995: 487). Patton (2002: 552, 553) states that credibility depends on the rigorous methods for fieldwork that yield high-quality data that are systematically analyzed with attention to the credibility of the researcher which is dependent on training and presentation of self, as well as to the philosophical belief in the value of qualitative inquiry. In the study the trained facilitator followed the guidelines for NGT strictly as described by Delbecq, Van de Ven and Gustafson (1975: online). Participant review was also used to ensure that the research findings were validated and verified for all qualitative data-gathering (Talbot, 1995: 488). During data collection the raw data were verified throughout the nominal group discussions to correct possible errors making sure the facilitator's understanding was correct (Nieuwenhuis, 2007: 113). Triangulation can further enhance credibility (Polit and Beck, 2004: 431). It overcomes the intrinsic bias that comes from using a single method and observer. This was done by collecting data about the same phenomenon at different points in time (time triangulation) and at multiple projects (space traingulation), and presenting the data at project level, as well as at a study level (person triangulation) (Polit and Beck, 2004: 431).

Once credibility was established dependability could be demonstrated. **Dependability** refers to the stability of data over time. When dependability is ensured it enables someone else to follow the process and procedures that the researcher used in the study (Talbot, 1995: 488). The nominal groups were all done in the manner described in section 3.3.4.2. The researcher was evaluated by an expert in group facilitation at the UFS to assess the researcher's ability to conduct a nominal group. The evaluation was done during the nominal group conducted at Botshabelo as part of the pilot study. Furthermore, the researcher trained and observed the fieldworker facilitator during several nominal groups.

Dependability is further ensured by the provision of the data to enable an inquiry audit (see annexures 12 and 13). An inquiry audit involves the scrutiny of data and relevant supporting documents (Polit and Beck, 2004: 435). Demonstrating dependability leads to the assurance of confirmability.

Confirmability refers to the objectivity of the data (Polit and Beck, 2004: 435). It guarantees that the findings, conclusions and recommendations of the study are supported by the data (Talbot, 1995: 488). The facilitator of the nominal groups acted objectively and allowed respondents to analyze the data themselves. The analysis of the multiple-groups was peer reviewed to ensure different experts came to the same conclusion as the researcher (Van Breda, 2005: online). Content analysis was used to identify themes from the data generated by the twelve groups. These themes were discussed and finalized during a group discussion with the researcher and three experts in the field of HIV-related research.

The last criteria to demonstrate trustworthiness is transferability.

Transferability refers to which findings can be related to other settings (Polit and Beck, 2004: 435). Talbot (1995: 488) suggests keeping a detailed dataset and a description to explain the researcher's conclusions. This was done. During the case selection the projects were selected in such a manner that the sample could be regarded as representative of the population (Berg, 2007: 44 and Welman, Kruger and Mitchell, 2005: 69). The sample was therefore composed of elements that contained the most typical attributes of the population (De Vos *et al*, 2005: 202). The researcher furthermore described the background of the four MOC projects in full detail in Chapter 1 and throughout the study for the conclusions to be interpreted in a specific setting.

The study was done in three phases, namely: preparation, data collection and the conclusion. Discussions of the implementation of the three phases follow.

3.2. Phase I - Preparation

Before the study commenced the researcher had to do extensive preperation as recommended by Soy (1997: online) as depicted in Figure 3.1.

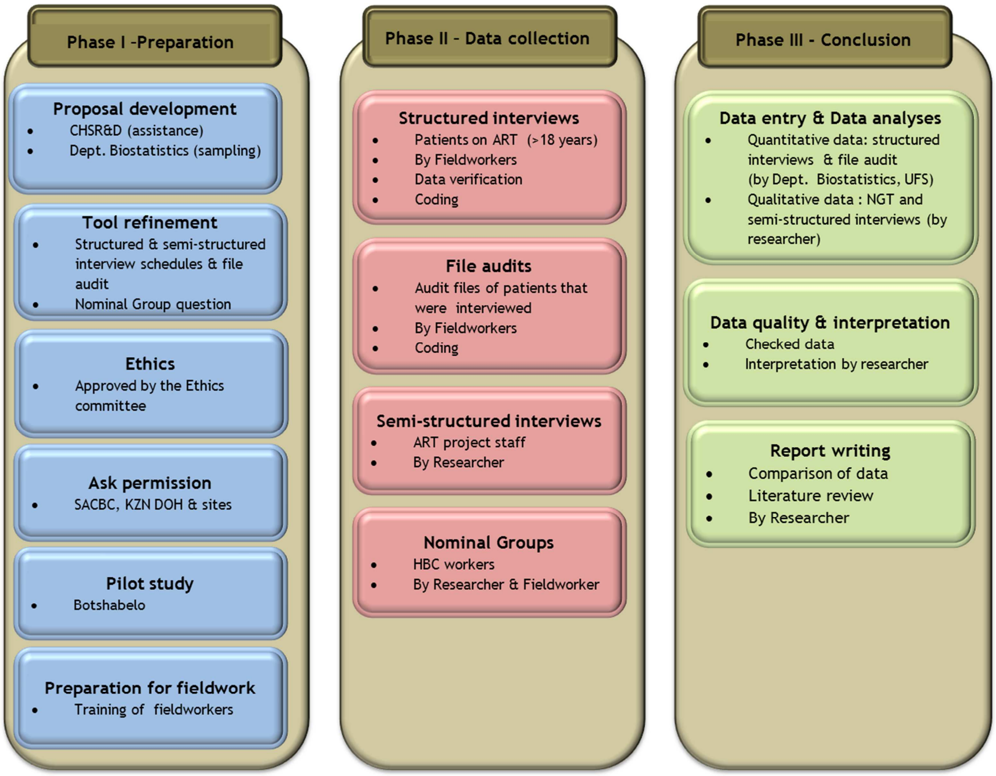


Figure 3.1 Overview of the study

3.2.1. Proposal development

The researcher was part of the MOC study (Engelbrecht *et al*, 2008) that was conducted in the Free State (see section 2.2) and therefore had access to the data-gathering tools and the analysis that was done for the study. The proposal development of this study was therefore done in conjunction with the CHSR&D at the UFS. The researcher selected four projects within the SACBC ART program to do the study. Sampling for the study occurred at different phases. First the researcher selected four projects (cases). Hereafter the Department of Biostatistics from the UFS assisted with the sampling of the number of patients who had to be interviewed. The sampling of participants and respondents will be discussed in Phase II in conjunction with the data collection methods used.

3.2.1.1. Case selection (sampling of projects)

Sampling is a process of selecting elements for participation in a study from the target population identified (Burns and Grove, 2005: 34, 342). Patton (2002: 46) states that it is typical of a qualitative inquiry to focus on relatively small samples, even single cases, selected purposefully to permit inquiry into and understanding of a phenomenon in depth. A small sample size may better serve the purpose to examine a situation in depth from various perspectives. A small sample of cases was selected from ART projects managed by the SACBC. The four projects were purposefully selected. The logic and power of purposeful sampling lies in selecting information-rich cases making an in depth study possible. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling. Studying information-rich cases yields insight and in-depth understanding rather than empirical generalization (Patton, 2002: 230). The researcher thus consciously selected certain subjects or elements to include in the study. Efforts were made to include typical subjects or typical projects (Burns and Grove, 2005: 325). The researcher relied on her knowledge and experience, working closely with these projects for nearly three years prior to the study, to deliberately select cases. Using purposeful sampling might introduce bias and would mean that the researcher was not able to generalize fully to all the cases in the population as the sample was not randomised. Purposeful sampling, however, is a strength of a qualitative study as it enables the researcher to focus. Patton (2002: 235) further describes the maximum variation sampling strategy. The strategy aims at capturing and describing the central themes that cut across a great deal of variation. For small samples, a great deal of heterogeneity can be a problem because individual cases are so different from one another. The maximum variation sampling strategy turns that apparent weakness into a strength. While the evaluation would describe the uniqueness of each project (MOC), it would also look for common themes across them. Any such themes take on added importance precisely because they emerge out of great variation. Thus, when selecting a small sample of great diversity, the data collection and analysis will yield two kinds of findings: 1) high-quality, detailed descriptions of each case, which are useful for documenting uniqueness, and 2) important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity.

At the time of the study the SACBC managed twenty ART projects (population) in South Africa. The projects were stratified into four MOC types. A project (case) was purposefully selected from each type of MOC to reflect the most typical cases. The small sample allowed the researcher to study the SACBC program in depth and the impact of the different MOC on ART delivery (George *et al*, 2010: 78). Table 3.1 depicts the selection frame. The four projects represented projects providing facility-based care, community-based care as well as projects that operated in different relations to the SAG. The four MOC identified were:

- ✓ NGO Project: Facility-based centralized services
- ✓ NGO Project: Community-based decentralized services
- ✓ NGO Project: In close collaboration with SAG
- ✓ Public Private Partnership: Partnership between the SAG and the NGO

Table 3.1 Case selection

Project name	**Town**	**Providence**	**District**
NGO PROJECT: FACILITY-BASED CENTRALIZED			
Blessed Gerard Care Centre	Mandeni	KZN*	Ilembe
Good Samaritan Hospice	Cradock	Eastern Cape	Chris Hani
Good Shepherd Hospice	Middelburg	Eastern Cape	Chris Hani
Holy Cross Home	Pretoria	Gauteng	Tshwane
Hope for Life	***Winterveldt***	***Gauteng***	***Tshwane***
Inkanyezi project	Orange Farm	Gauteng	West Rand
Kurisanani	Tzaneen	Limpopo	Mopani & Vhembe
Nazareth House	Johannesburg	Gauteng	Johannesburg
Newcastle ART project	Newcastle	KZN*	Amajuba
Sinosizo	Amanzimtoti	KZN*	Ethekwini
Siyathokoza *(Pilot project)*	Botshabelo	Free State	Motheo
St Francis Care Centre	Boksburg	Gauteng	Ekurhuleni
St Joseph Care and Support Trust	Bronkhorstspruit	Gauteng	Metsweding
NGO PROJECT: COMMUNITY-BASED DECENTRALIZED			
Mtubatuba	Mtubatuba	KZN*	Umkhanyakude
Tapologo	***Rustenburg***	***North West***	***Bojanala***
NGO PROJECT: CLOSE COLLABORATION WITH SAG (SEPARATE NGO)			
Bela-Bela HIV & AIDS prevention group	***Bela-Bela***	***Limpopo***	***Waterberg***
St Mary's Hospital	Durban	KZN*	Ethekwini
PPP: PARTNERSHIPS BETWEEN THE SAG AND SACBC (SAG PROJECT)			
Bisdom VIGS Ministerie	Keimoes	Northern Cape	Namakwa & Siyanda
Sisters of Mercy	Bethal	Mpumalanga	Gert Sibande
St Apollinaris Hospital	***Creighton***	***KZN****	***Sisonke***

*KZN = KZN

Each of these MOC will be described briefly:

1) NGO PROJECT: FACILITY-BASED CENTRALIZED SERVICES

A NGO-managed project providing ART services at a centralized point. HBC workers assist patients in communities around the facility, but ART services are provided at the centralized formal structure, such as a clinic. The project selected was Hope for Life in Winterveldt, Gauteng. The project provided ART to 357 patients at the time.

2) NGO PROJECT: COMMUNITY-BASED DECENTRALIZED SERVICES

A NGO-managed project providing ART services at a decentralized point. HBC-workers assist patients in communities and on specified dates ART services are provided in "facilities." The facilities such as a local church or freight container might not be designed for the provision of healthcare. Administration of the project is centralized (at a "head office"), but ART services are provided in the communities. These ART services are similar to a type of "mobile clinic" services used in PHC. The project selected was Tapologo, outside Rustenburg in North West, serving 698 ART patients at the time.

3) NGO PROJECT IN CLOSE COLLABORATION WITH SAG

A NGO-managed project providing ART services in close collaboration with a public facility. The ART services are funded through the NGO. Although the services are delivered on the same premises as the public funded health project the ART project is a parallel project. The NGO has access to public resources with full control of the ART project. The project selected was the one in Bela-Bela, Limpopo, providing ART to 349 patients at the time.

4) PUBLIC PRIVATE PARTNERSHIP: PARTNERSHIP BETWEEN THE SAG AND THE NGO

ART provision is managed by the DoH at a public facility. Drug procurement and laboratory services are provided by the SAG. The SACBC funded NGO is assisting the SAG with the public roll out of ART. The NGO does not have full control over the ART project. The project selected was the St Apollinaris Hospital (based on the Centocow Mission) near Creighton in KZN (KZN) serving 1,024 ART patients at the time.

As part of the research proposal data-gathering tools had to be developed. The researcher refined established tools used in the study by Engelbrecht *et al* (2008).

3.2.2. Tool refinement

As part of the mixed method approach used in the study several data-gathering tools were used. Before the study commenced the structured interview, file audit and the group work with the HBC-workers were refined or changed.

3.2.2.1. Tool refinement of the structured interview schedule

The structured interview schedule was developed in conjunction with staff at the CHSR&D at the UFS. The questionnaire used in the MOC study (Engelbrecht *et al*, 2008) conducted by the CHSR&D was adapted. Both close-ended and open-ended questions were use. Closed-ended questions (structured, fixed response) provide the respondent with a list of predetermined responses. Open-ended questions (unstructured, free response) elicited the respondent's own answer to the question (Neuman, 2006: 287; Babbie and Mouton, 1998: 148). The interview schedule is available for review in Annexures 8.

The following additions were made to the structured interview schedule used by Engelbrecht *et al* (2008) to ensure the phenomenon studied could be fully understood.

- ✓ The respondents were asked if they were Catholic to determine if the Catholic projects provided access to patients from different religious affiliations and not only to Catholics.
- ✓ Questions related to the socio-economic indicators of the respondents were closely aligned with the dataset used in the Stats SA questionnaires. Although the original structured interview had the socio-economic questions the researcher added some options to the close-ended questions to align the questions with the dataset used by Stats SA.
- ✓ Questions related to food security were added to the income and education section. The questions related to social grants were broadened to include other than disability grants.
- ✓ A section on the QOL of the respondents was added. The questions used were those of the EuroQol system (EuroQol Group, n.d.: online) consisting of a descriptive system (EQ-5D) that measures health-related QOL on five dimensions (mobility, self-care usual activities, pain/discomfort, and anxiety/depression) and a 20 cm vertical visual analogue scale (EQ VAS) that generates a self-rating of health-related QOL. Clinical trials, observational studies and other health surveys widely use the EuroQol system (Szende, Oppe and Devlin, 2010: 7).
- ✓ The section on ART initiation was expanded to include details of previous exposure to ART.
- ✓ Questions regarding prophylaxis (Cotrimoxazole) were added.
- ✓ Questions regarding alcohol use were added as alcohol use can negatively influence adherence to ART.

The finalized refined structured interview schedule contained the following sections (see annexes 8):

✓ Demographic and biographic information	section 2
✓ Socio-economic indicators	section 3

✓ Income and education	section 4
✓ Quality of Life	section 5
✓ Facility accessibility	section 6
✓ Care and support received	section 7
✓ Antiretroviral therapy	section 8
✓ Alcohol use	section 9
✓ Hospitalization	section 10
✓ Retention in care	section 11
✓ Quality of care	section 12
✓ Vertical care	section 13
✓ General	section 14

The file audit (record review) was also refined.

3.2.2.2. Tool refinement of the file audits

The study done by Engelbrecht *et al* (2008) had a limited set of questions regarding the respondent's file. The record review in the original study had limited clinical questions focusing on the record-keeping done, the last laboratory tests done and the next appointment of the patient.

The clinical data required were expanded to include all the laboratory tests and the weight and height of the respondents. The researcher also included data related to adherence and retention. This enabled the researcher to focus on the clinical outcome of the respondents in the study. The additional data elements were based on annual program evaluation by Professor Robin Wood at the University of Cape Town. The file audit schedule (section 15) is part of the interview schedule (see annexures 8).

The study by Engelbrecht *et al* (2008) made use of focus groups to inquire about the recruitment, training, clinical roles, experiences and personal perceptives of lay workers.

3.2.2.3. Tool refinement of the group technique

The researcher decided to use the NGT instead of the focus group technique as the technique allows for participant participation in the analysis of the data (theme identification and voting). The NGT is a structured variation of small-group discussion methods (like the focus group). The NGT process prevents the domination of discussion by a single person, encourages more passive persons to participate and results in a set of prioritized solutions or recommendations (De Long, 2004: online). The nominal group question used was "*What do you need to be a good HBC-worker*".

The last data-gathering tool used was the semi-structured interview schedule.

3.2.2.4. Tool refinement of the semi-structured interview schedules

The MOC study by Engelbrecht *et al* (2008) used two semi-structured interview schedules: the HCW- and facility semi-structured interview schedules. Only open-ended questions (unstructured, free response) were used prompting the respondent's own answer to the question (Neuman, 2006: 287 and Babbie and Mouton, 1998: 148). The interview schedule is available for review in Annexures 9 and 10.

The HCW interview schedule (Annexures 9) inquired about:

✓ The demographic details of the respondent	Q 4-6
✓ The work experience and training received by the respondent	Q 7
✓ The daily roles performed	Q 8

✓ Major frustrations experienced	Q 9
✓ Problem solution strategies in use	Q 10-16
✓ The respondent’s opinions of the MOC	Q 17

The facility interview schedule (Annexures 10) inquired about:

✓ Physical space and location	section B
✓ Staff structure, roles, training and support	section C
✓ Protocols, guidelines and standard operating procedures	section D
✓ The extended care process	section E
✓ Information management	section F
✓ Pharmacy and Laboratory services	sections G,H
✓ Links with other services	section I

The ethical considerations for the study included the design of the data-gathering tools and continued to emerge in every phase of the research process (Talbot, 1995: 489). After the completion of the proposal and the refinement of the data-gathering tools the researcher obtained the necessary permission from the Evaluation Committee within the School of Nursing. Thereafter the researcher applied for ethics approval from the ethics committee of the Faculty of Health Sciences at the UFS.

3.2.3. Ethical considerations

The Nuremberg Code and Declaration of Helsinki and various nursing codes guide nursing research to ensure the ethical treatment of research participants (Talbot, 1995: 40-41). Researchers have an ethical obligation to their study population (Berg, 2007: 53). The ethical treatment of respondents in the study will be discussed in this section. The researcher started with obtaining ethics approval.

3.2.3.1. Ethics committee approval

Neuman (2006: 131) reminds researchers that the researcher's authority to conduct research, granted by professional communities and the larger society, is accompanied by a responsibility to guide, protect, and oversee the interests of the people being studied. Researchers should therefore submit their research plan to the appropriate ethics committee for review prior to beginning a study (Brink, 2001: 39). The design, data-gathering tools and proposed methodology of the study were submitted to the ethics committee of the Faculty of Health Sciences at the UFS for evaluation and approval. Ethical considerations were given to an array of principles. Burns and Grove (2005: 735) summarize the three principles relevant to conducting ethical research as respect for human dignity, beneficence, and justice.

3.2.3.2. Principle of respect for human dignity

The principle of respect for human dignity indicates that persons have the right to self-determination and the freedom to choose to voluntarily participate or not participate in the study, without the risk of penalty or prejudicial treatment (Babbie, 2007: 26; Burns and Grove, 2005: 181, 187, 750; Brink, 2001: 39). The respondents therefore received adequate information on the goal of the interviews, the procedures, possible advantages and disadvantages before data collection commenced (full disclosure) (De Vos *et al*, 2005: 59). Individuals had the right to make decisions without the coercion of others (autonomy) and without risk or harm to the person (non-maleficence) (Talbot, 1995: 37).

Respondents were not directly approached by the researcher or fieldworkers associated with the study. The project manager or other professional staff at the projects explained the purpose of the study to potential respondents. The patients had the option to opt-out (take the option out) of the study. Those who did not opt-out were interviewed by trained fieldworkers. HBC-workers and

HCWs were approached by the project manager on behalf of the researcher. Before commencing data collection the fieldworkers/researcher discussed and provided respondents with a copy of the research information sheet (see annexures 4 and 8) and obtained written informed consent from the respondents (see annexures 5 and 9). Informed consent is the prospective subject's agreement to participate in a study as a subject, which is reached after assimilation of essential information (Burns and Grove, 2005: 193).

Neuman (2006: 135) states that obtaining informed consent is a fundamental ethical principle and that nobody should be coerced into participating. Participation should be voluntary. It is not enough to ask permission: they need to know what they are being asked to participate in so that they can make an informed decision. To promote the respondents' understanding the consent forms were available in English, Zulu and Tswana. Data were collected from patients and HBC-workers in their language of preference. To avoid any coercion the respondents did not receive any monetary incentive. The HBC-workers received lunch before or after the group sessions as they had to wait for the sessions.

3.2.3.3. Principle of beneficence

The principle of beneficence encourages the researcher to do good and above all to do no harm, by protecting the respondents from discomfort and harm (Babbie, 2007: 27; Burns and Grove, 2005: 190, 728; Brink, 2001: 40). The responsibility to protect against harm reaches further than mere efforts to minimize such harm, to thoroughly inform the respondents of the potential impact of the intervention (De Vos *et al*, 2005: 59). Respondents can be harmed physically or emotionally. The study did not impose any physical harm on the respondents, but recalling personal details can be emotionally stressful. Further the data collection can be an intrusion into the respondents' lives as they were asked to reveal personal information (that could be potentially embarrassing) to a stranger (Babbie, 2007: 62, 63). When refining questions particular care was taken to ensure that the questions posed to respondents were carefully phrased to minimize emotional distress (Polit and Beck, 2004: 144). The respondents were informed of the potential risk and that they could refuse to answer a question or discontinue the interview at any time. Neither would the information obtained during the interviews/groups be used against them (Polit and Beck, 2004: 144).

Burns and Grove (2005: 191) urge the consideration of the balance of benefits and risks in a study. The degree of risk in participation should never exceed the benefits of the knowledge gained in the study (Polit and Beck, 2004: 147). The benefit of the study is that four MOC for ART delivery by a FBO will be described, analyzed and compared. The study would inform future program planning, healthcare and policy development which will lead to more relevant care and improved access to treatment being provided. The only risk that the study will cause is temporary discomfort. The discomfort will cease with termination of the interview. The researcher balanced the associated benefits and risks of the subject's participation in the study (Talbot, 1995: 37). Although the data collection can be upsetting to some, the benefits of participation in research should not be underestimated either (Gibbs, 1997: 5). The opportunity to be involved in decision-making processes and to be valued as experts can be empowering for many respondents.

3.2.3.4. Principle of justice

The principle of justice includes the respondents' right to fair selection, treatment and privacy (Burns and Grove, 2005: 189, 740; Brink, 2001: 40). The respondents should be selected for reasons directly related to the problem being studied and any agreements made with subjects should be respected (Brink, 2001: 40). Privacy is the right an individual has to determine the circumstances under which personal information will be shared with or withheld from others (Burns and Grove, 2005: 186). The research should not be more intrusive than it needs to be (Polit and Beck, 2004: 149). The respondents should be assured that their privacy will be protected by the protection of their identity.

In the study respondents associated with the four MOC were asked to participate. Anonymity (the guarantee that the respondent will remain nameless) could not be guaranteed for the respondents, during data collection, as the fieldworkers/researcher collected the information from an identifiable respondent (Babbie, 2007: 65). Confidentiality was, however, assured. Confidentiality is an active attempt to remove elements that might indicate the respondents' identity. In cases where the researcher can identify a given respondent's responses the researcher promises not to do so publicly and intentional precautions should be taken to ensure that information does not accidently fall into the wrong hands (Babbie, 2007: 65; Berg, 2007: 79, 81). When conducting the structured interviews confidentiality was ensured by numbering all the structured interviews as well as the informed consent sheets. The respondents' identity had to be known to the fieldworker who conducted the file audit in order to retrieve the respondent's file (discussed in section 3.3.2.1). Once the file audit was done the informed consent form was separated from the interview schedule and kept safely by the researcher. Only the researcher had access to the respondents' names beyond the data collection stage. The semi-structured interview schedules contained the names of respondents. These were safely stored and only the researcher had access to these schedules.

The respondents' information was thus protected from public disclosure (Neuman, 2006: 139). The information obtained was not discussed at respondent level, ensuring confidentiality of the respondents. The respondent's privacy was respected by conducting data collection in private settings. The infrastructure did not always allow for private rooms to be used. Interviews were done outside the facilities. Care was taken to ensure that respondents could not hear other respondents' responses. The same measures applied to the file audit as for the structured interview. In addition, the fieldworker and the researcher were very careful to handle the respondents' patient files with the utmost respect. Semi-structured interviews were conducted in private offices, while nominal groups were held away from other people.

Respondents were treated fairly and were given the assurance that they could withdraw at any time and that support would be available after data collection if they would like to talk to someone (De Vos *et al*, 2005: 305).

After receiving ethics approval the researcher had to seek permission from different relevant stakeholders to conduct the study.

3.2.4. Ask permission to conduct the research

Permission to conduct research was obtained from the Director of the SACBC AIDS Office, the managers of the five (including the pilot project) facilities and the chairperson of the provincial health research committee of the DoH in KZN (see annexures 2). Permission from the DoH in KZN was necessary as St Apollinaris Hospital is based in a public facility in KZN.

After obtaining permission from all the relevant stakeholders the researcher conducted a pilot study at the Siyathokoza ART Project in Botshabelo.

3.2.5. Pilot study

A pilot study involves a small sample of subjects drawn from the same population as those from which the study sample will be drawn (Talbot, 1995: 74). The researcher conducted the pilot study at the Siyathokoza ART project in Botshabelo. Siyathokoza was part of the population for this study and one of the projects described in the study by Engelbrecht, *et al* (2008). The refined tools discussed in section 3.2.2 were piloted. The fieldworkers used at Siyathokoza in the CHSR&D study were used again to pilot the structured interview schedule and file audit schedule. Ten patient structured interviews, ten file audits and one nominal group were conducted at Siyathokoza. The nominal group was done by the researcher. A senior lecturer from the School of Nursing at the UFS was present during the nominal group to observe the researcher's ability to conduct group work. No changes were made to the refined tools. The semi-structured interview schedules were not piloted as there were no changes made during the refinement phase and the schedules had been used at Siyathokoza during the original study.

After the pilot study was done the final preparations had to be done before the researcher could collect the data.

3.2.6. Preparation to do fieldwork

Before the fieldwork could commence the researcher had to set up a final fieldwork schedule, print the data-gathering tools, recruit and train the fieldworkers.

3.2.6.1. Setting the fieldwork schedule

An assessment of the time schedules of the selected projects was done and arrangements were made to visit the projects. Table 3.2 tabulates the fieldwork schedule used for the study.

Table 3.2 Fieldwork schedule

Project	Date from	Date to	# of fieldworkers	Language of preference
St Apollinaris	26 November 2007	10 December 2007	6	Zulu
Hope for Life	14 January 2008	24 January 2008	7	Tswana
Tapologo	4 March 2008	17 March 2008	7	Tswana
Bela-Bela	25 March 2008	4 April 2008	7	Tswana

3.2.6.2. Printing the final interview schedules

Participants' main language capabilities were identified and the structured interview schedule, the information letters and consent forms were translated into Zulu and Tswana. The documents were back translated to English by independent translators to ensure that the language versions were correct and conveyed the exact same message. The structured and semi-structured interview schedules were printed and bound.

The last important task before data-gathering could start was the recruitment and training of the fieldworkers.

3.2.6.3. Recruiting and training the fieldworkers

A group of fieldworkers accompanied the researcher on each fieldwork trip. The group consisted of fieldworkers (responsible for collecting data using structured interviews) and a data quality assistant. In addition, one of the fieldworkers was trained to do nominal groups; two additional fieldworkers were trained to do file audits. A data quality assistant was responsible for checking completed structured interview schedules and coding of the structured interview schedules and file audits.

Fieldworkers for the first two trips were recruited from the School of Nursing at the UFS. Third year nursing students were interviewed and selected based on language proficiency and an aptitude for interviewing patients. At the end of the second trip the majority of the nursing students had to withdraw from the team due to academic responsibilities. Fieldworkers for the last two trips were recruited from Catholic ART projects, other than the projects under study. The fieldworkers were lay staff working with ART patients. These fieldworkers were also interviewed and came highly recommended from their projects of origin. For the first trip to Centocow Mission (St Apollinaris Hospital) all the fieldworkers had to be fluent in Zulu. The subsequent groups had to be fluent in South Sotho and Tswana.

The same fieldworker assisted with the facilitation of the nominal groups in all four trips. The data quality assistant from the first trip had to be replaced due to her work commitments at the CHSR&D. The replacement assistant accompanied the teams on the remaining three trips. The first data quality assistant was the data quality assistant at the CHSR&D. The second data quality assistant was a third year nursing student.

The different groups of fieldworkers who accompanied the researcher on the trips are depicted in photograph 3.1.

Photograph 3.1 Fieldworkers taking part in the study

Before each fieldwork trip new recruits were trained. The fieldworkers had to complete a two-day theoretical training session. During the two days the fieldworkers were trained on:

- ✓ Interview techniques.
- ✓ Professional conduct (attitude, dress code during fieldwork, no eating in front of the participants, the use of cellphones, etc.).
- ✓ Confidentiality.
- ✓ How to obtain informed consent and the content of the information letters.
- ✓ The content of the structured interview schedule and how to ask the various questions contained in the schedule.

Practical role play sessions were held after the training and during debriefing meetings in the evenings. Debriefing meetings were held every evening during the fieldwork. Fieldworkers could discuss challenges they had had during the day. The researcher and data quality assistant could address concerns they had had with the fieldwork.

Training for the file audits occurred while in the field. A staff member of the project would provide orientation to the researcher, the data quality assistant and two additional fieldworkers on how to retrieve information from the monitoring and evaluation system used at the project. The researcher would then work with the small team until she was satisfied that the workers knew how to retrieve the required information. File audits were mostly done after hours.

The fieldworker trained to assist with the facilitation with the nominal groups was trained during the first fieldwork trip. The training was done by going through the theoretical work (steps of the nominal group); hereafter a practice group was conducted using fellow fieldworkers. The researcher observed the first two nominal groups she facilitated at St Apollinaris as well.

After the preparation phase was completed the data collection commenced.

3.3. Phase II – Data collection

Data collection is the precise, systematic gathering of information relevant to the research purpose and the specific objectives or questions of a study (Burns and Grove, 2005: 42). The key strength of the case-study method lies in the use of various data collection techniques as is typical of a mixed method design (Yin, 2003: 97; Patton, 2002: 297; Soy, 1997: online). The techniques that were used and the evidence that needed to be collected were determined in advance in order to answer the research questions. Although data collection was largely qualitative the methods used enabled the researcher to obtain information on both qualitative and quantitative data without the limitation of using a single data collection technique (Soy, 1997: online). The rationale for using both qualitative and quantitative data was to provide a comprehensive analysis of the research problem (Creswell, 2003: 16).

During the data collection phase the researcher and a group of trained fieldworkers visited each project for 14 – 20 days at a time (see Table 3.2 for schedule). This approach was determined by the embedded single case-study method where, within a single case, attention was given to subunits (Yin, 2003:42).

Consent was obtained from the relevant management and Church structures before the fieldwork commenced (see section 3.2.4). On the day of arrival the research team was introduced to the staff at the project and the purpose of the study was explained. A program for data collection (that caused the minimum disruption) was finalized with the project manager.

Data were collected through various techniques: structured and semi-structured interviews, file audits and nominal groups.

3.3.1. Structured interviews

Berg (2007: 92) identified three major categories of interviews: the standardized (formal or structured) interview, the un-standardized (informal or nondirective) interview, and semi-standardized (guided semi-structured or focused) interview. The major difference between these different interview structures is their degree of rigidity with regard to presentational structure. Structured interviews were used to obtain data from patients in the ART projects at the selected projects.

The fieldworkers had to adhere strictly to the interview schedule and were not allowed to change the sequence of questions, but they were allowed to clarify questions.

3.3.1.1. Population and sampling for structured interviews

The total number of ART patients in each project (population) was used to draw the sample of patients to be interviewed. The sample was drawn in collaboration with the Department of Biostatistics at the UFS. Inclusion criteria for selection of patients were that they had to be older than 18 years of age, be on ART in the project and give consent. Stratified sampling was used to determine the number of respondents who had to be interviewed.

The population (patients on ART at the project meeting the inclusion criteria) was divided by gender (strata). Within each stratum, independent sampling was conducted proportionally (Maree and Pietersen, 2007: 175). Once in the field, quota sampling was used to select participants. Sampling was done by means of convenience sampling until the quotas were reached (Maree and Pietersen, 2007: 177). To enhance the representativeness of the sample, the sample selected was of sufficient size (Mouton, 2002: 139). The Macorr sample-size online calculator confirmed that the sample size would deliver a confidence level of 95% and a confidence interval of 5% (Macorr Research Solutions, n.d.: online). The population and sample size are tabulated in Table 3.3. The sample represented an average of 38.25% of the total population.

Table 3.3 Sample frame for structured interviews

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	Total
Population (Jun 2007)	**980**	**305**	**648**	**313**	**2,246**
Sample	276	170	241	173	860
Males in sample	88	51	72	56	267
Females in sample	188	119	169	116	592
% of population	28.16%	55.74%	37.19%	55.27%	38.25%
Total interviewed	**324**	**210**	**287**	**185**	**1,006**
Males interviewed	87 *(-1)**	68 *(+17)***	80 *(+8)***	61 *(+5)***	296 *(+29)***
Females interviewed	237 *(+49)***	142 *(+23)***	207 *(+38)***	124 *(+8)***	710 *(+118)***

* A negative number indicates that the proportional sample size was not met. ** A positive number indicates that the proportional sample size was surpassed.

3.3.1.2. Data collection of structured interviews

A group of trained fieldworkers conducted structured interviews with the patients. These fieldworkers were able to speak the preferred language of the patients. The fieldworkers were of the same or similar socio-economic background. At least one male fieldworker was in a group for instances where patients felt uncomfortable speaking to a female fieldworker.

Staff from the project introduced the research team each morning after morning prayers. The purpose of the study was explained. Patients had the right to opt-out of participating in the study. Patients who were willing to participate were asked to present themselves to the researcher or the data quality assistant. Respondents were then assigned to a fieldworker who could speak a language the respondent felt comfortable using.

Interviews were conducted outside the ART facilities. The fieldworker was equipped with two chairs, a clip board and a pen. Fieldworkers had to make sure that other individuals around the project could not hear their conversations with the respondent. After explaining the information letter and obtaining consent the fieldworkers followed the structured interview schedule.

Once the interviews were completed the fieldworker thanked the respondent and the completed schedule and the consent form were brought to the researcher or the data quality assistant. The schedules were then checked for completeness. If any problems were found the respondents were still in the vicinity of the facility and could be approached by the fieldworker. Fieldworkers were remunerated per completed, verified schedule.

At St Apollinaris and Tapologo some of the schedules were discarded due to data quality problems as illustrated in table 3.3. This can be attributed to the fact that the majority of fieldworkers were new when the fieldwork was done at these two projects.

Table 3.4 Number of structured interviews conducted

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	Total
Interviewed	340	210	287	185	1,037
n	324	210	302	185	1,006
Interview schedules discarded	16	0	15	0	31

After verifying the data on the schedule, the respondent’s file would be drawn in order to complete the file audit. Once the file audits were completed the schedules were coded by the data quality assistant and the researcher and filed separately from the consent forms. The data were processed and analyzed at the end of the study.

3.3.1.3. Data analysis of structured interviews

Information obtained by the structured interviews was analyzed by a biostatistician at the Department of Biostatistics at the UFS State. Before analysis the schedules were sent to Information and Communication Technology Services on the UFS campus to be captured. They captured the data twice and compared the datasets in order to verify that the data were captured correctly. Data checking was done by the biostatistician before the data analysis begun. Data checking ensures whether missing information is really missing and whether answers not making sense and need amendment.

Descriptive statistics, namely frequencies and percentages for categorical data and medians and percentiles for continuous data, were calculated per project. The projects were compared for continuous data by means of 95% confidence intervals for the median difference. The analysis was generated using SAS software (Copyright, SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, USA).

File audits were done for all the respondents who participated in the structured interviews.

3.3.2. File audits

All the patient files of the respondents who participated in the structured interviews were audited. Clinical data relating to the respondent’s clinical outcome were collected. Records represent a particularly rich source of information and are a valuable learning resource (Patton, 2002:293-394). In contemporary society, all kinds of entities leave a trail of paper, a kind of spoor that can be mined as part of fieldwork. Yin (2003:85) states that documentary information is relevant to every case-study topic and because of their overall value, documents play an explicit role in data-gathering when doing case studies.

3.3.2.1. Population and sampling for file audits

The population comprises the respondents who were interviewed using the structured interview schedule. All the respondents' files were audited (see section 3.3.1.1). Sampling was therefore not done.

3.3.2.2. Data collection of file audits

Data were collected from respondents' patient files at the project. Once a structured interview was completed, the consent form with matching questionnaire number was used to acquire the respondent's patient file. A trained fieldworker assisted the researcher to record the required data on the audit schedule. Annexure three contains a sample of the file audit schedule.

3.3.2.3. Data analysis of file audits

Information obtained by the file audits was also analyzed by the same biostatistician at the Department of Biostatistics at the UFS State who analyzed the structured interviews data. The file audits were part of the procedure described in section 3.3.1.3.

3.3.3. Semi-structured interviews

Semi-structured interviews are interviews organized around areas of particular interest, while still allowing considerable flexibility in scope and depth (De Vos *et al*, 2005: 292, 296). Considerable freedom is allowed, although the researcher had a set of predetermined questions on an interview schedule to guide questions. The researcher could answer questions for clarification, adjust language used and could add or delete probes (Berg, 2007: 93).

Two semi-structured interview schedules were used. The first schedule was the HCW interview schedule, designed to interview HCWs regarding their work experience within the project and the second was the facility interview schedule designed to interview the management of the project regarding the operation of the project. See section 3.2.2.4 for more detail regarding the content of these schedules.

3.3.3.1. Population and sampling for semi-structured interviews

For the facility interview the researcher interviewed the project managers (no more than 2 individuals per project). HCW (registered nurses, doctors etc.) interviews (no more than 15) were conducted until saturation of information occurred. Saturation occurs at the point in the study where the researcher begins to hear the same information repeatedly and no longer hears anything new and further information becomes redundant (Burns and Grove, 2005: 750; De Vos *et al*, 2005: 294). Table 3.5 tabulates the number of semi-structured interviews that were conducted.

Table 3.5 Semi-structured interviews conducted

	St Apollinaris	**Hope for Life**	**Tapologo**	**Bela-Bela**	**Total**
Manager (Facility assessment)	1	1	1	1	**4**
Registered nurses (HCW interview)	3 of 3	2 of 2	7 of 10	1 of 2	**13 of 17**
Doctor (HCW interview)	1 of 1	0 of 1	1 of 2	2 of 2	**4 of 6**
Other (HCW interview)	2	2	1	1	**6**

Data collection among the HBC-workers was done by the researcher on an appointment basis.

3.3.3.2. Data collection of semi-structured interviews

Appointments were made with the project staff to ensure the data collection process would not disrupt their work or any patient care. Interviews were conducted in the staff member's office or consultation room. Informed consent was obtained before the interview commenced. Semi-structured interview schedules were completed and stored safely for data analysis.

3.3.3.3. Data analysis of semi-structured interviews

Data were analyzed by the researcher. Data analysis is conducted to reduce, organize and give meaning to data (Burns and Grove, 2005: 733). In order to do this, the information obtained from the staff members was tabulated, summarized and reported on in the research report.

The last data-gathering tool was the NGT.

3.3.4. Nominal groups

Nominal Groups are a structured method for group brainstorming that encourages contributions from everyone (Tague, 2004: 96). The technique is very effective in generating a large quantity of creative new ideas. It is designed to allow every member of the group to express their ideas and minimizes the influence of other participants (Delbecq, Van de Ven and Gustafson, 1975: online). Nominal groups were held to obtain ideas from groups of HBC-workers on an issue in a structured format (De Long, 2004: online).

3.3.4.1. Population and sampling of NGT

HBC-workers working in the ART projects were invited to participate in the nominal groups because they have certain characteristics in common that relate to the topic of the study and because they are knowledgeable and experienced with regards to the topic under investigation (De Vos *et al*, 2005: 300; Welman, Kruger and Mitchell, 2005: 204). At each project the HBC coordinator was asked to request the HBC-workers to come for the NGT sessions. After the HBC-manager introduced the researcher and the facilitator she left. Informed consent was obtained and the information sheets discussed before the groups began. None of the HBC-workers declined to participate.

Twelve nominal groups were held (to the point of saturation) during the study (2 groups at St Apollinaris, 2 groups at Hope for Life, 5 groups at Tapologo and 3 groups at Bela-Bela). Eleven themes were identified. The size of the groups was between seven and nine respondents with a maximum size of about 12 people as recommended by Delbecq, Van de Ven and Gustafson (1975: online).

3.3.4.2. Data collection through NGT

Nominal groups conducted were done by a facilitator with the researcher present. A trained fieldworker facilitated the groups. The fieldworker (facilitator) holds a B.Soc.Sc degree in Psychology from the UFS and is fluent is Zulu (her mother tongue), Sotho and Tswana. One of the groups at Bela-Bela had to be done in Afrikaans. Here the researcher assisted. Group discussions were held in the participants' language of preference. Main ideas were written in the language of preference and English (if English was not the language of choice) and the rest of the notes only in English. The groups actively participated in the translation efforts. With assistance from the group, the facilitator served as the group recorder, while following the NGT format closely (Delbecq, Van de Ven and Gustafson, 1975: online). Groups were held in various locations (meeting rooms, empty waiting areas, open waiting areas and under the trees) as summarised in photograph 3.2. Great care was taken to ensure the respondents' privacy was secured and that others could not hear what they were saying.

Photograph 3.2 Nominal group activities

Delbecq, Van de Ven and Gustafson (1975: online) suggest seven steps for Nominal Group Meetings. After the facilitator asked the participants to sit in a small group, each participant was supplied with pen and paper. The following steps were then followed:

1. The facilitator *stated the subject of the brainstorming* and clarified the statement where necessary.
2. *Silent writing of ideas* on question. To provide focus, time for creativity without interruptions, avoid conformity, competition and status problems, and avoid evaluation and jumping to conclusions.
3. *Round-robin recording of ideas on chart*. This forced equal sharing and participation encourages more ideas; "hitch-hiking" depersonalizes ideas and tolerates conflicting ideas.

4. *Clarification of each idea on chart.* Each statement was clarified by the participants and notes were recorded. All statements were treated with equal importance.
5. *Grouping of ideas.* The facilitator grouped ideas together and allowed respondents to provide focus on important issues.
6. *Vote on priorities.* Respondents were given five cards each. They were asked to give the idea they support the strongest, five marks (and the idea they support thereafter four marks etc.).
7. *Tally marks and give results.* The marks were tallied and checked and the results were given to the respondents. Providing the respondents with the analyzed data promoted a sense of accomplishment and conclusion and should motivate involvement in future efforts.

The respondents were very positive about the interactive process followed.

3.3.4.3. Data analysis of NGT

The preliminary data analysis was done during the group meetings. Using content analysis (where ideas are grouped under major headings) the participants were asked to vote on major headings at the end of the group meetings (Delbecq, Van de Ven and Gustafson, 1975: online), producing twelve sets of nominal group data. A method described by Van Breda (2005: 4-11) was used to analyse the data generated by the multiple-groups (see annexures 10 for data). The following steps were followed to analyze the multiple NGT data:

1. *Capturing the data in an excel spreadsheet.* Information included was the group number, statements and the scores.
2. *Identifying the top five statements of each group.* This indicated the priorities of each group.
3. *Content analyses.* Content analysis is a careful, detailed, systematic examination and interpretation of a particular body of material in an

effort to identify themes (Berg, 2007: 304). The statements from all the groups were grouped into themes by the researcher; these themes were discussed and finalized during a group discussion with the researcher and three experts (an expert in NGT, an expert in qualitative research and the person who analysed data for the CHSR&D study) in the field of HIV-related research.

4. The themes discussed in number 3 were added to the spreadsheet.
5. *Calculating ranks.* Using the top five ranking, the number of statements per theme and the average score as voted for by the participants the most important themes were identified.
6. *The data are reported in Chapter Six.*

In the final phase of the research the research report was written after the data were entered and analyzed.

3.4. Phase III - Conclusion

Data entry and analysis for the structured interviews (n=1006) and the file audits were done by the Department of Biostatistics of the UFS. The data analysis was discussed under each individual data collection technique. The research findings are reported in Chapters Four and Six, with the conclusions recorded in Chapter Seven. When interpreting data the ultimate goal is to arrive at findings and draw conclusions. Each conclusion must be based on substantiated findings from the data that are reported in relation to what is already known so as to reveal possible new insights or validation of existing knowledge (Nieuwenhuis, 2007: 113). These findings were made within certain limitations.

3.5. Limitations of the study

Limitations of this study have been discussed in the document. Here follows a summary of these limitations.

- ✓ Philosophical approach.
    - The philosophical approach of the researcher might be an advantage when doing qualitative research; however, it might lead to bias when conducting quantitative research.
    - Scientific methods were used to collect data through trained fieldworkers and by utilizing triangulation.
- ✓ Using fieldworkers to collect data.
    - To limit errors in measurement fieldworkers were trained and the data was verified by a data quality assistant on-site before submission of the schedule.
- ✓ Qualitative data collection.
    - To limit errors in measurement the researcher received training from experienced researchers at the School of Nursing, UFS.
- ✓ Case selection.
    - A stratified purposive sample was used to select the four projects for the study due to the design and purpose of the study.
    - Findings could thus not be generalized to the entire population of patients in the SACBC program.
- ✓ Population.
    - There are significantly more female patients on treatment than male patients. Specific sampling procedures were used to compensate for this.
    - Some HBC-workers were illiterate and needed additional assistance in order to participate in the study. The researcher and the facilitator assisted the HBC-workers throughout the voting

process with recording. It was important to give these individuals the opportunity to participate, while benefiting from the use of the technique.

- ✓ Pilot study.
    - o A pilot study was not done at each project. The pilot study was only conducted at Botshabelo.

PART II

With the background of Catholic healthcare and the methodology used in the study described, the next part of the document will discuss the data gathered during the study. The data were presented in the order the field work was conducted (St Apollinaris, Hope for Life, Tapologo and Bela-Bela). Chapter Four focuses on the access to care and the profile of the patients who were able to access care and participated in the study. Chapter Five described the continuum of care provided at each MOC while Chapter Six focuses on the providers of care at the different MOC.

CHAPTER 4: ACCESSING CARE

Access to treatment is one of the major challenges to care and treatment in the developing world (Paredes, Sherer and Clotet, 2008: 444). In 2003 the World Health Organization introduced the "3 by 5 target" (to reach 3 million people by 2005 with ART). This goal was not reached until 2007 (AVERT, n.d.: 2). Countries aspired as part of a wider objective to provide universal access to treatment by 2010, with most countries aspiring to reach 80% of the individuals in need of ART. Although this goal was not reached, great gains have been made in the fight towards increased access to ART (AVERT, n.d.: 1). Despite tremendous efforts only 56% (49%-63%) of all HIV-infected patients worldwide, in need of ART, had access to the treatment in 2010 (United Nations Program on HIV/AIDS, 2010: 98). In SSA, the worst affected region in the world, only 37% of people in need of ART were reached by 2010 (AVERT, n.d.: 2). Apart from having less access to treatment, patients in SSA were also found to initiate ART late which limits the impact of the treatment. UNAIDS (2010: 29) ascribes the lack of access to treatment at the appropriate time partly to poor infrastructure available in these settings.

Chapter Four focuses on access to care. In this chapter the facilities available to the different MOC, the access to these facilities, and the patients who were able to access care will be discussed.

4.1 Infrastructure

When the ART roll-out started in South Africa, national accreditation was required before a healthcare facility could provide ART. Accreditation criteria of service points were set out in the *Comprehensive Plan* (South Africa, National

Department of Health, 2003). This process had to be rigorous and was aimed at strengthening the health system as a whole. Facilities had to have "appropriate numbers" of consultation rooms to assure patient confidentiality, although the number was not stipulated (South Africa, National Department of Health, 2003: 95). Access to "appropriate" laboratory services and adequate pharmacy storage and cold-chain capacity to handle schedule five drugs was also required (South Africa, National Department of Health, 2003: 99). The then Minister of Health (Dr Tshabalala-Msimang) highlighted the "lack of appropriate accommodation particularly for confidential consultation" as one of the challenges that the DoH had identified in the health system with regard to the provision of quality health services (South Africa, Department of Health, 2005: online).

Space limitations were experienced at all the facilities within the study. One of the main contributors to the space limitations in facilities in this study is the fact that facilities were not built with the ART project in mind, but were rather the result of FBOs improvising to provide care in existing infrastructure. From 2004 the AIDS Office (the group within the SACBC that coordinated the Church's response to HIV & AIDS in Southern Africa) implemented the AIDSRelief program in South Africa as an implementing partner of the AIDSRelief consortium. The AIDS Office was supporting about one hundred projects involved in HIV. Twenty of these projects were chosen to begin providing ART. Projects with the leadership and ability to manage an ART project were selected. Additional donor funding was used to strengthen the capacity and infrastructure at each project. Projects had their own unique identity and had good reach into the communities they served. The implication of this was that the ART services were added to existing programs. Furthermore, the ART provision was "shaped" according to the special needs of the communities they served, meaning that no two projects operated in exactly the same way. This flexibility allowed the projects to follow innovative ways to provide services, while following the National Department of Health's guidelines as far as possible.

Facilities available to the projects were, however, not designed for the provision of ART. Structures available to the projects were determined by the history of these projects.

4.1.1. The background of the facilities at St Apollinaris Hospital

St Apollinaris Hospital, situated on the Centocow Mission premises, is a public district hospital and has provided general healthcare to the surrounding areas since 1926. It was one of the 48 Catholic hospitals established in South Africa in the early 1900's, and was handed over to the management of the SAG in 1990 (CATHCA, 2011: 61), but has continued to work in partnership with the Church ever since. Buildings on the hospital premises were old and inadequate for additional healthcare at the hospital. In 2005 the Provincial DoH provided a small five room parkhome (a prefabricated structure) for the project. Space became a serious challenge again quickly and in 2006 and 2007 two additional parkhomes were donated through the SACBC to ease some of the space limitations of the ART project.

4.1.2. The background of the facilities at Hope for Life

Hope for Life is one of many projects initiated by the Sisters of Mercy in the Winterveldt area. The Mercy Sisters have worked in the former Bophuthatswana homelands since 1981 and established projects in the Winterveldt area to assist the needy. As the area was part of the homelands under the previous government, services were lacking and the Sisters delivered much needed healthcare, education and development activities in the area. Hope for Life's ART project developed out of a network of PHC clinics and HBC groups that the Sisters managed in the area. Patients are identified and assisted in the community by the HBC groups. ART provision was initially done at a centralized clinic (with one distribution point). A separate building on the premises of the Mercy Clinic was used to host the ART project.

4.1.3. The background of the facilities at Tapologo

Tapologo HIV & AIDS Program was born in 1997 to provide “a place of peace and rest” to those infected with HIV. The project is under the auspices of the Bishop (Bishop Kevin Dowling) and works in the area with the blessing of the Queen Mother of the Bafokeng people. Sr Georgina Boswell (a Religious Sister and a Registered nurse) had started providing PHC services in the informal settlements near the platinum mines in 1993. With the help of a local doctor (Dr van Schalkwyk) they even provided midwifery services that are now managed by the SAG DoH. Tapologo was started to address the needs of the HIV-affected in the area. Tapologo manages care and support projects in eight outreach areas around the platinum mines, with the majority of these outreach projects housed in informal structures.

4.1.4. The background of the facilities at Bela-Bela

Ms Cecile Manhaeve who has been working in the Bela-Bela community since 1996 established the Bela-Bela HIV prevention group (hereafter referred to as Bela-Bela). The prevention group has focused on the education of people around Bela-Bela regarding HIV. A large number of the counselors are HIV-infected and the group sourced funding from Belgium to start the staff on treatment. Wooden structures (Wendy houses) on the premises of the public PHC clinic in Bela-Bela served as offices and treatment rooms. Once the PEPFAR funding was secured services were expanded to the Bela-Bela, Spa Park and Vingerkraal communities.

The above mentioned four ART projects were developed for different reasons and have very different facilities available. The physical structures available for the implementation of the ART projects will be discussed next.

4.1.5. Physical structure

In spite of the fact that the facilities of the SACBC projects were unable to meet the rigid accreditation requirements as set out in the *Comprehensive Plan* (South Africa, National Department of Health, 2003: 95-99), they initiated and maintained ART treatment for thousands.

4.1.5.1. Physical structures available at St Apollinaris Hospital

The Ethembeni Clinic at St Apollinaris Hospital is situated in two park homes, next to the St Apollinaris District Hospital. Photograph 4.1 shows the Ethembeni Clinic's parkhomes. The park home on the left (1) is the clinic that consists of three consultation rooms, a waiting area (used to do training and clinical screening), a small kitchen and a staff toilet. Park home number two (on the right) is shared by a social worker, staff from the rape survivor counseling project as well as the monitoring and evaluation unit.

Photograph 4.1 A view of Ethembeni Clinic's two parkhomes

Photograph 4.2 shows the inside of the Ethembeni Clinic. Here the waiting area and the door to the first consultation room can be seen. Two registered nurses share this consultation room. Therefore, privacy cannot be ensured because consultations occur simultaneously.

Photograph 4.2 The inside of the Ethembeni Clinic

The physical space at Hope for Life was as limited as that at St Apollinaris Hospital clinic.

4.1.5.2. Physical structures available at Hope for Life

Hope for Life Clinic is situated in a three room brick building behind the Mercy Clinic that was built by the skill development project run by the Sisters of Mercy. Photograph 4.3 shows the front view of the small ART clinic.

Photograph 4.3 The front view of the Hope for Life ART Clinic

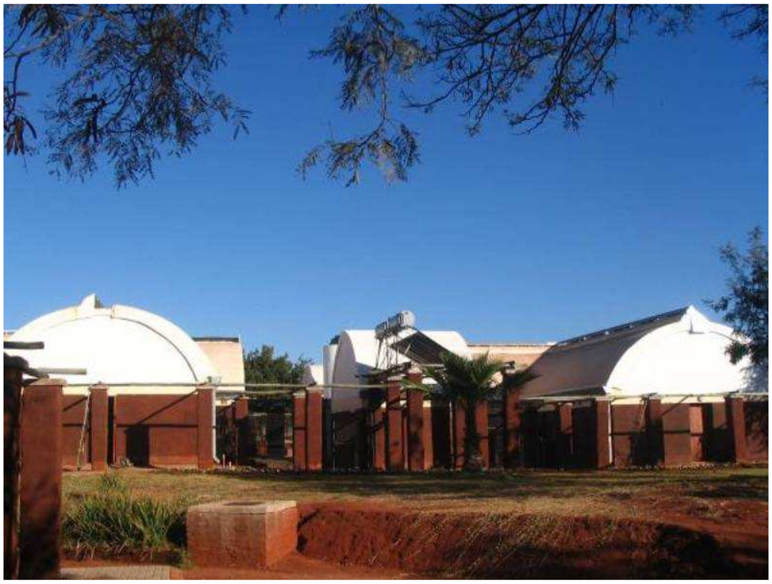
Photograph 4.4 shows the main waiting area with a patient entering through the left door in Photograph 4.3. The waiting area is also used for adherence counseling (table on the right, red arrow), an administrative area (yellow arrow) and patient education (chairs). Two consultation rooms can be accessed through the door on the right.

Photograph 4.4 The inside of the waiting area at Hope for Life

The Tapologo projects make use of a variety of facilities scattered around the platinum mines outside Rustenburg.

4.1.5.3. Physical structures available at Tapologo

At Tapologo the administrative offices are centralized, while ART services are decentralized in the community. Photograph 4.5 is of the centralized offices and hospice that were built from natural materials in the area.



Photograph 4.5 A front view of the centralized offices at Tapologo

Staff members, carrying files and equipment, travels on a daily basis from the centralized offices to different outreach clinics that are housed in freight containers or old buildings. Here follows an overview of five of the eight "clinics". The other three clinics look similar to these described below.

Photograph 4.6 The Freedom Park ART Clinic

Photograph 4.6 is shows the Freedom Park ART Clinic housed in a freight container while Photograph 4.7 shows the inside of the only consultation room at Freedom Park.

Photograph 4.7 The inside of the consultation room at Freedom Park

Some of the ART clinics are based on Church property. Photograph 4.8 shows the clinic at Phokeng which is situated near the centralized offices in an old building. Many of the clinics are small, with serious space limitations. Waiting areas are outside the clinic, thus alleviating the space problem and assisting with TB infection control.

Photograph 4.8 The front view of the building at Phokeng Clinic

An elementary, but private, nurse's consultation room exists at Phokeng and is shown in Photograph 4.9.

Photograph 4.9 The consultation room at Phokeng Clinic

Tlaseng's Clinic is based in one room at the back of a local supermarket. On the left the outside waiting area can be seen. Photograph 4.10 shows the local store with the clinic on the left side of the building.

Photograph 4.10 The building that houses the Tlaseng Clinic

Photograph 4.11 The inside of the Tlaseng Clinic

Photograph 4.11 shows the inside of the Tlaseng Clinic. Consultations at the Tlaseng Clinic are done behind a screen in the large room available to the project.

At the Ledig "Clinic", near Sun City, healthcare services are provided outside and are therefore very vulnerable to the elements. The administration and counseling is done "under the tree" (red arrow) as can be seen in Photograph 4.12.

Photograph 4.12 The location where the Ledig Clinic is held

Consultations are done in an informal structure (shack) in the back of the yard that also serves as a storage facility for chairs and tables used during clinic days (see Photograph 4.13). The staff bringing the medical equipment comes from the central Administrative Office on clinic days.

Photograph 4.13 The informal structure used as a consultation room at Ledig

The Kanana Clinic consists of two freight containers and a shack on the grounds of the Kanana Parish at the local Catholic Church. Photograph 4.14 is a front view of the Kanana Clinic.

Photograph 4.14 The Kanana Clinic

The Chaneng Clinic consists of three rooms in an old abandoned government clinic shown in Photograph 4.15. Another group in the same building sells prepaid electricity.

Photograph 4.15 The front view of the Chaneng Clinic

At Bela-Bela the majority of the ART activities are based at the main clinic outside Bela-Bela.

4.1.5.4. Physical structures available at Bela-Bela

The Bela-Bela HIV prevention group operates from a set of “Wendy houses” at the back of the local government PHC clinic (see Photograph 4.16). It is these wooden structures and the respect the community has for her that afforded Cecile Manhaeve (founding member and project manager) the nick name of “Ma Plankie”. A yellow arrow indicates the finance office. The green arrow indicates the open waiting area (TB DOTS project from the “stoep”). From the open waiting area the door leads to two consultation rooms used for HIV counseling and testing (HCT). A red arrow indicates the manager’s office and the doctor’s consultation room.

Photograph 4.16 The Bela-Bela facility at the main project.

Photograph 4.17 shows the inside of the consultation room at the main Bela-Bela project.

Photograph 4.17 The inside of the Bela-Bela consultation room

Bela-Bela has two satellite sites. Photograph 4.18 shows the informal structure (shack) from where HBC and adherence support is coordinated in Vingerkraal. All medical related consultations are done at the clinic in Bela-Bela. Vingerkraal is an informal settlement about 50km outside Bela-Bela. A group of Ovambu people was re-located here after 1994.

Photograph 4.18 The informal structure in Vingerkraal

The second satellite is in Spa Park outside Bela-Bela. Photograph 4.19 shows HBC-workers coming together outside the community hall in Spa Park. Counseling is done at this location while all medical related consultations are done at the clinic in Bela-Bela

Photograph 4.19 The building used in Spa Park

The infrastructure available to each project is very different. To summarize the researcher tabulated some of the main characteristics of the infrastructure available in Table 4.1.

4.1.5.5. Infrastructure available summarized

Table 4.1 reflects the infrastructure available to the different projects. Hope for Life is the only project using a brick building. The majority of the other facilities are semi-structured (parkhomes or freight containers) or informal structures (shacks). St Apollinaris has the largest number of patients on ART and notably the least space. The decentralized project (Tapologo) has the most space, although the space is often informal and waiting areas and consultation areas are outside.

Table 4.1 Infrastructure available at ART provision point

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Structure of ART provision points	Park home	Brick building	Freight containers, informal structures, old brick buildings	Wooden Wendy houses
# ART patients end June 2007	1,074	357	698	349
ART dispensed at # of provision points	1	2	8	1
# consultation rooms	3 (at main site)	2 (at main site)	mean = 1, maximum = 3	2
# counseling rooms	1*	1	Majority outside	2
Waiting area	Small (inside), open waiting area	Large inside, no open waiting area	No inside, all open waiting areas	No inside, open waiting area
ART provision at	Hospital *	2 Clinics	All at distribution points	Clinic
ART provision centralized	Yes (1 satellite planned for stable ART referrals*)	Yes (1 satellite – only stable ART referrals)	No (all services provided at outreach sites)	Yes (ART provision and consultations only at main site)

*An outreach project was planned for at the time

Apart from the physical space and structure of the facilities available, the actual location of the facilities also impacts on the access to care for the patients.

4.2. Location

To determine how accessible the facilities were, the proximity to public transport or the availability of transport was investigated. It was found that all the facilities are on public transport routes. At St Apollinaris the public transport was at times insufficient, especially during the rainy season. Hope for Life and Bela-Bela provided some patient transport. The Tapologo patients and the majority of the Bela-Bela patients lived in close proximity to the ART provision facilities. Table 4.2 reflects the proximity of the facilities to public transport, the areas where patients reside and whether the project provides transport.

Table 4.2 Public transport and transport needs

ART Facility in relation to:	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Public transport	On route, transport can be scares, influenced by weather	On route	On route	On route
Majority of patients reside	Away from facility in mountainous area	Away from facility, coming from villages where HBC provided	Near the facilities, clinics in the villages	Majority near the facility, two smaller groups away from facility
Transport provided	Limited	Scheduled patients and HBC-workers	To staff	To patients and HBC-workers from areas away from facility

All the facilities are on public transport routes. The St Apollinaris Hospital is secluded and approximately 19 km from the tar road between Underberg and Bulwer. On rainy days public transport is a problem. Tapologo provides better access to patients as the satellites were situated in the villages when the ART services were decentralized. Hope for Life and Bela-Bela provide scheduled transport to patients from outlying areas to the centralized ART service points.

Once the patients reach the facility, access is influenced by whether the facility is in operation.

4.3. Hours of operation

The *Comprehensive Plan* (South Africa, National Department of Health, 2003: 98) requires ART facilities providing ART to be open 24-hours a day, or have access to 24-hour care in the vicinity. Table 4.3 tabulates the operating hours of the different projects.

Table 4.3 Operating hours for ART provision

	St Apollinaris	**Hope for Life**	**Tapologo**	**Bela-Bela**
In-patient care	Yes (Hospital), at ART facility	No	Yes (Hospice), away from ART facilities	No
Days ART provision/ consultation	Weekdays	Monday – Thursday	Monday- Thursday (not every day at every site)	Monday – Friday (some after hours)
Staff available for unscheduled visits/emergency on non-ART days	24 hours at Hospital	Friday focus on administration tasks, staff available at site	Friday focus on admin tasks, staff not available at site	Clinic open after hours for pre-booked specialist consultation
Hours of operation per day	8	8	8	8 +

At Hope for Life and Bela-Bela, the projects do not provide 24-hour access. Patients at these projects need to visit public facilities in the area after hours and on weekends. The Bela-Bela project is, however, based on the same stand at the SAG PHC clinic. The Tapologo patients can visit the Hospice or the local public facilities. Access is a problem due to the distance to these facilities.

The patients who accessed care the day of the interview were asked if they experienced any problems accessing the facility.

4.4. Patients' experiences of problems with access

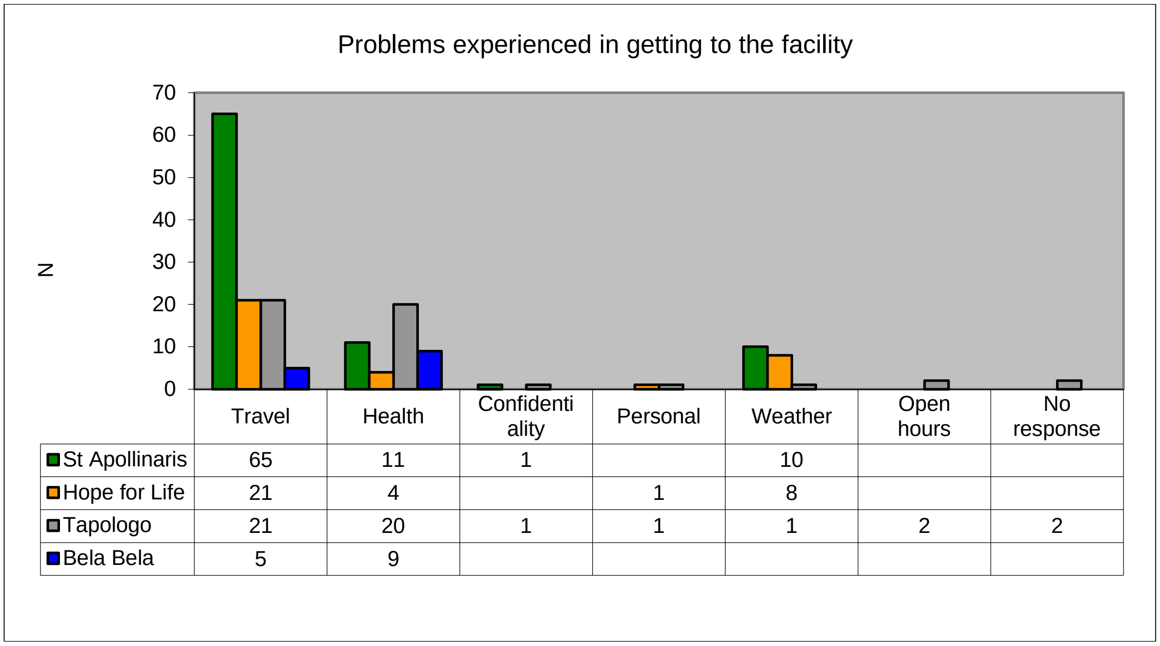
The majority (84.89%, n=854) of the patients did not experience any problems accessing the facility they attended on the day of the interview. Table 4.4 reflects whether the respondents experienced any problems with access to the facility.

Table 4.4 Problems experienced with access to the facility

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
No problems	**79.01% (n=256)**	**84.76% (n=178)**	**86.41% (n=248)**	**92.97% (n=172)**	**84.89% (n=854)**
Problems	20.99% (n=68)	15.24% (n=32)	13.59% (n=39)	7.03%(n=13)	15.11% (n=152)

The level of problems experienced notably varied between the projects. More than twenty percent (20.99%, n=68) of the respondents at St Apollinaris experienced problems accessing the facilities with less than ten percent (7.03%, n=13) of the respondents at Bela-Bela experiencing problems.

Respondents were asked what kind of problems they experienced in getting to the health facility; their answers are depicted in Figure 4.1.



	Travel	Health	Confidentiality	Personal	Weather	Open hours	No response
🟩 St Apollinaris	65	11	1		10		
🟧 Hope for Life	21	4		1	8		
▨ Tapologo	21	20	1	1	1	2	2
🟦 Bela Bela	5	9					

Figure 4.1 Problems experienced with accessing the facility

Travel was experienced as the biggest problem in accessing the facilities, with some problems caused by the patient's health status and weather conditions on the given day. Both the problems with the weather and health status can be problems related to travel. Problems with access would not be as profound in bad weather or in ill health if suitable transport were available. Problems related to travel are also more permanent, as the patients' health should improve as they continue to take ART, while weather fluctuates and is not a constant problem. Table 4.5 provides more information on the time, mode and cost of traveling to the facility.

Table 4.5 Travelling to the facility

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Time travelled	Minimum	3 min	**> 49 min**	< 1 min	< 2 min	< 1 min
	Median	**1hour 52 min**	1 hour	½ hour	½ hour	1 hour
	Maximum	**45 hours**	20 hours	30 hours	4 hours	45 hours
Mode	Walked	9.57% (n=31)	**22.86% (n=48)**	**65.85% (n=189)**	**81.62% (n=151)**	**41.65% (n=419)**
	Taxi	**79.94% (n=259)**	**63.81% (n=134)**	**28.92% (n=83)**	9.73% (n=18)	**49.11% (n=494)**
	Own transport	3.09% (n=10)	4.29% (n=9)	3.48% (n=10)	3.24% (n=6)	3.48% (n=35)
	Lift (free)	1.23% (n=4)	1.90% (n=4)	0.70% (n=2)	0.54% (n=1)	1.09% (n=11)
	Lift (paid)	3.40% (n=11)	0.00% (n=0)	1.05% (n=3)	0.00% (n=0)	1.39% (n=14)
	Project transport	2.47% (n=8)	5.71% (n=12)	0.00% (n=0)	4.32% (n=8)	2.78% (n=28)
	Other	0.30 (n=1)	1.43% (n=3)	0.00% (n=0)	0.54% (n=1)	0.50% (n=5)
Cost	Minimum	0	0	0	0	0
	Median	**R17.00**	R6.00	0	0	R6.00
	Maximum	R150.00	**R200.00**	R52.00	R56.00	R200.00

Respondents at St Apollinaris had more severe problems with travelling to the facility as nearly 80% (79.94%, n=259) of the respondents had to take a taxi to the facility, travelling for nearly 2 hours (median = 1 hour 52 minutes) to get to the facility at a cost of an average of R17.00 (median = R17.00). At Hope for Life more than 60% (63.81%, n=134) of the respondents had to pay for a taxi to take them to the facility; all the respondents travelled for more than 49 minutes and paid around R6.00 (median = R6.00) for the trip. Tapologo respondents had fewer problems travelling to the facilities. More than two-thirds (65.85%, n=189) could walk and would reach the facility within a half an hour (median = 30 minutes) with the majority of respondents not paying for transport (median = R0.00). Bela-Bela respondents reported the fewest problems travelling to the facilities. 81.62% (n=151) of the respondents could walk to the facility and reach it within a half an hour (median = 30 minutes), with the majority of respondents not paying for transport (median = R0.00).

The problems with travel can be ascribed to the distance to the ART facilities and the hidden costs to access care (e.g. paying for transport). The projects situated in a small location (Bela-Bela) and with decentralized services (Tapologo) reported fewer problems with travel. Travelling from distant areas to the facility with costly transport competes with other essential costs and challenges the patients' ability to collect drugs (Gusdal *et al*, 2009: 1383). Gusdal *et al* (2009: 1385) agree that the cost of transport can be overcome by developing satellite distribution points linked to an ART facility. This decongests the central facility and increases accessibility of services.

The *Comprehensive Plan* (South Africa, National Department of Health, 2003) (see section 4.1) not only prescribes the physical structures required; it includes the need for the "appropriate laboratory services and adequate pharmacy storage" needed at the facilities. These conditions are needed to ensure that when the patient accesses care the necessary treatment and monitoring is available.

4.5 Laboratory and pharmacy services

South Africa does not have enough pharmacists to provide quality pharmacy services countrywide (Misra and Cele , 2007: 44). To overcome this challenge the SACBC made the decision to make use of a centralized pharmacy in Gauteng for the projects receiving PEPFAR funded ART. Project staff placed an order via fax or e-mail with the centralized pharmacy after furnishing them with a prescription. A pharmacist at the centralized pharmacy dispenses the medication to individual patients and sends the patient treatment-packs through a courier to the relevant project. A registered nurse at the project opens and checks the medication before handing it to the patient (see Photograph 4.20). Original prescriptions or unused patient treatment-packs are returned with the courier to the supplier.

Photograph 4.20 A registered nurse handing out the patient's pre-packed ART at an SACBC project

At St Apollinaris the HIV-patients received (together with all the other hospital patients) their ART medication from the pharmacist at the main hospital pharmacy. Functioning as a district hospital, a fully equipped pharmacy is available at St Apollinaris.

Decentralization and integration of services at PHC level holds promise for improved access to treatment for patients. Centralization of service components (like pharmacy services) has also been successful in the roll-out in the public health services in the Free State (Van Rensburg *et al*, 2008: 8). Steyn *et al* (2009: 5) concluded that middle income countries with a good pharmaceutical sector do not have to set up parallel systems for supplying ART. Pharmaceutical systems could rather be upgraded and a centralized distribution point with transport to outlying areas could be successful. Table 4.6 indicates the difference between the SAG-based project (St Apollinaris) and the three NGO-managed projects in relation to pharmacy and laboratory services.

Table 4.6 Pharmacy and Laboratory services available at the projects

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Pharmacy	Pharmacy on-site	Yes	No	No	No
	Pharmacist available	Yes	No	No	No
	Dispensed from	Hospital pharmacy	Central pharmacy	Central pharmacy	Central pharmacy
	ART funded by	SAG	USG	USG	USG
Laboratory	Laboratory on-site	Yes	No	No	No
	Blood send away for	VL	All	All	All
	Test done by	NHLS	Toga Laboratories	Toga Laboratories	Toga Laboratories
	Test funded by	SAG	USG	USG	USG

* NHLS = National Health Laboratory Services, USG = United States Government

The laboratory services worked on a similar basis to the pharmacy services. The St Apollinaris Hospital had a laboratory on-site with limited capacity. Blood samples could be drawn on any week day. The blood samples for testing of VLs had to be sent to an off-site laboratory of the National Health Laboratory Service (NHLS). Turn-around times were prolonged and a VL test result could take up to a month to be released.

The three NGO-managed projects (Hope for Life, Tapologo and Bela-Bela) used a centralized laboratory service in Gauteng. Blood samples could only be taken on specified days and were then sent to the central laboratory by courier. Blood test results were emailed to the projects within days. Hard copies were sent with the courier service on the following collection date.

These centralized services increased the transport cost of the operation, but ensured a stable supply of antiretroviral drugs and access to high quality monitoring for the patients in remote areas.

When looking at access to care it is of significant value to determine the profile of the patients who accessed care.

4.6 Patient profile

This section will describe, analyze and compare the profiles of respondents reached by the four projects as set out in the aim of the study. De Haan (2005: 6) declares that a patient's health is influenced by environmental and psychosocial factors. The respondents (n = 1006) will be profiled according to these environmental and psychosocial factors in order to establish which patients had access to the four projects.

Accessibility to healthcare is crucial to enhance healthcare for the most impoverished (De Haan, 2005: 6). In order to establish if the most impoverished persons had access to the services offered by the projects, certain indicators of the respondents' profile will be compared to the 2007 Community and General Household Surveys conducted in South Africa by Statistics South Africa. A confidence interval of 95% for the prevalence will be indicated to establish if there is a difference between the respondents in the study and the general population of the municipality where treatment was accessed. Table 4.7 tabulates information concerning the local municipality, district and province the projects are based in.

Table 4.7 Location of the projects

Project	**Local municipality**	**District**	**Province**
St Apollinaris Hospital	Ingwe	Sisonke	KZN
Hope for Life	Tshwane	Tshwane	Gauteng
Tapologo	Rustenburg	Bojanala	North West
Bela-Bela	Bela-Bela	Waterberg	Limpopo

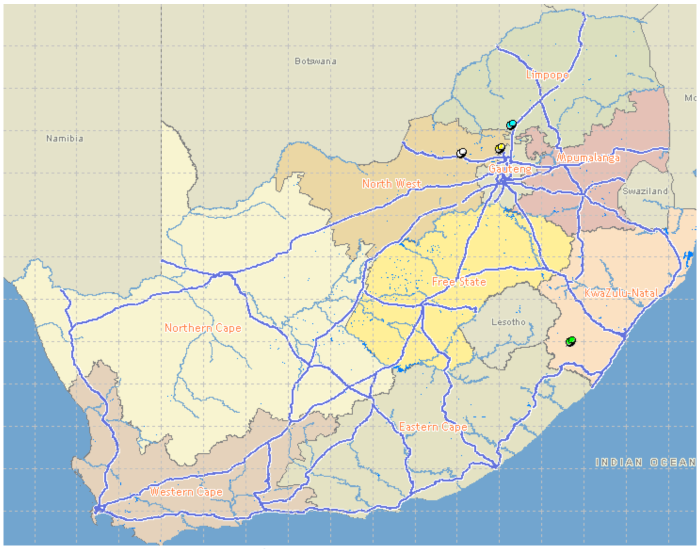


Figure 4.2 Location of projects

Figure 4.2 shows the location of the four projects on the South African map. St Apollinaris (green) in located in KZN, Hope for Life (yellow) in Gauteng, Tapologo (white) in North West and Bela-Bela (cyan) in Limpopo.

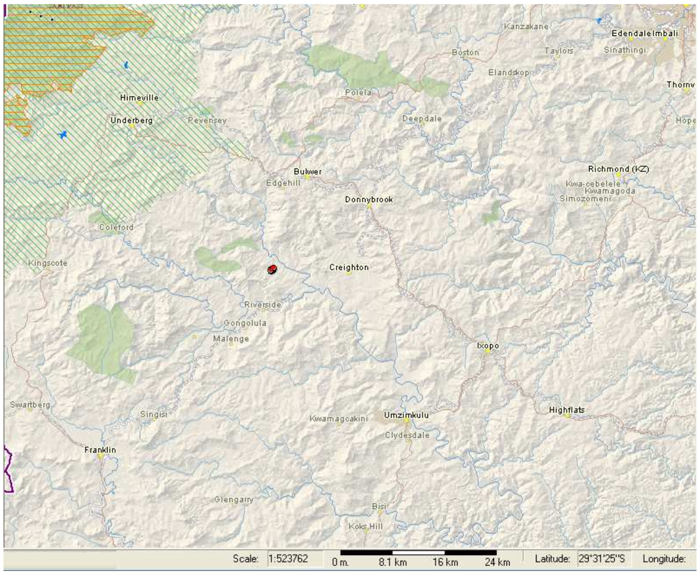


Figure 4.3 St Apollinaris Hospital

St Apollinaris (Government facility) is based in a very mountainous area of Sisonke District and had no satellite clinics at the time as shown in Figure 4.3.

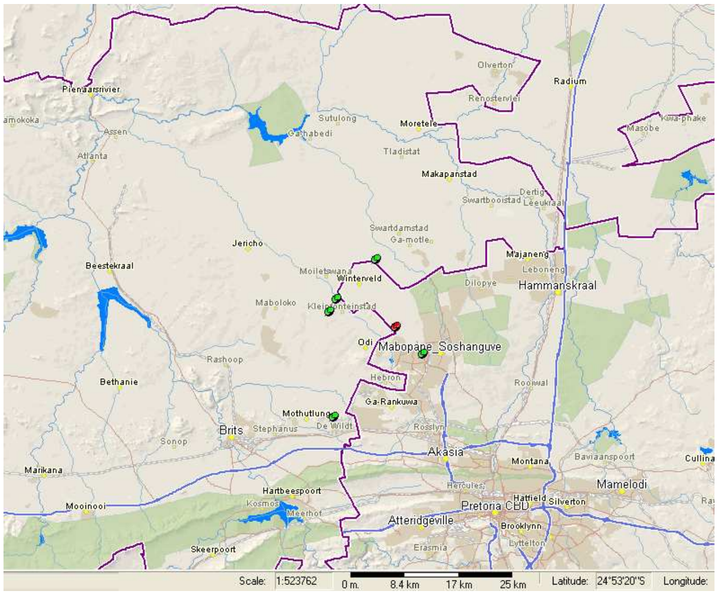


Figure 4.4 Hope for Life

Hope for Life was based at the Mercy Clinic (red) and also received patients from five (green) different HBC groups based at a network of Catholic clinics in the Winterveldt as seen in Figure 4.4 (ART centralized). Figure 4.5 demonstrates the set-up at Tapologo. The centralized administrative office in Phokeng (red) with seven satellite points where ART services were provided (ART decentralized).

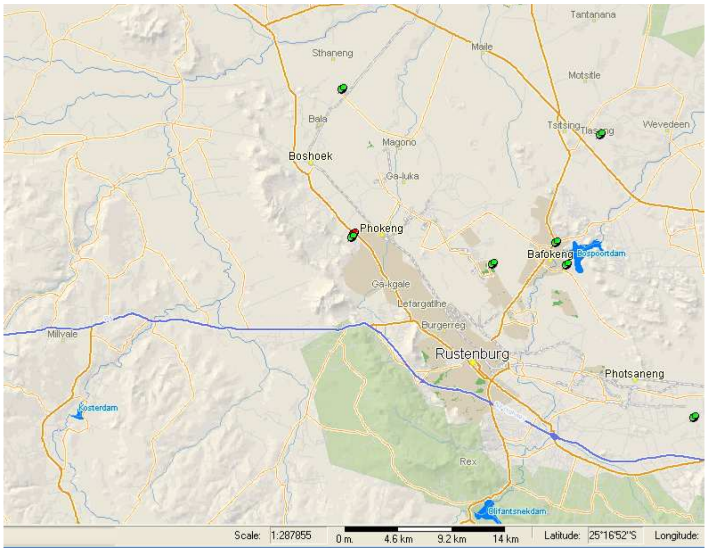


Figure 4.5 Tapologo

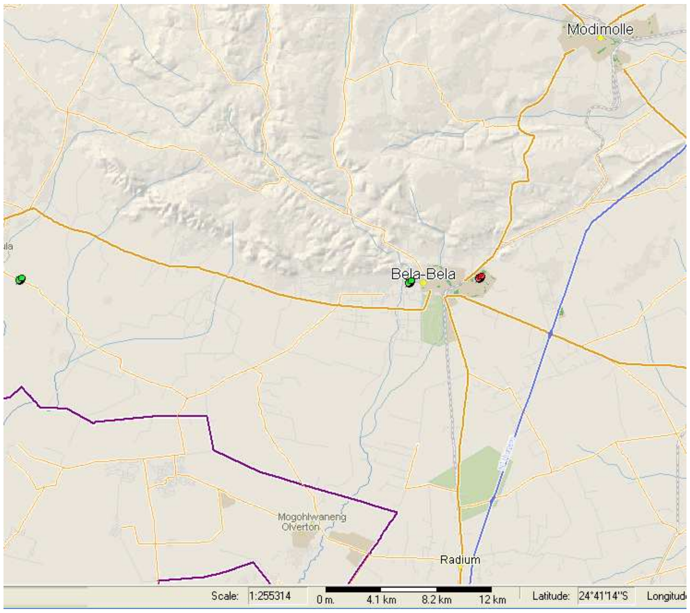


Figure 4.6 Bela-Bela

The group in Bela-Bela provided centralized ART at the main site in Bela-Bela (red) in close collaboration with the Government PHC clinic on-site. Two satellites (green) existed for HBC support as seen in Figure 4.6.

Following is the patient profile information.

4.6.1. Basic demographic data.

Data that reflect the respondents' gender, age, religious affiliation, mother tongue and relationship status are tabulated in Table 4.8.

Table 4.8 **Demographic data**

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Gender	Male	26.85% (n=87)	32.38% (n=68)	27.87% (n=80)	32.97% (n=61)	29.42% (n=296)
	Female	**73.15% (n=237)**	**67.62% (n=142)**	**72.13% (n=207)**	**67.03%(n=124)**	**70.58% (n=710)**
Age	Minimum	18.05	19.07	19.94	**21.13**	18.05
	Median	35.30	38.10	39.56	**39.10**	37.49
	Maximum	66.58	**77.44**	65.77	75.17	77.44
Religion	Catholic	39.51% (n=128)	8.10% (n=17)	35.89% (n=103)	13.51% (n=25)	27.14% (n=273)
	Non-Catholic	**60.49% (n=196)**	**91.90% (n=193)**	**64.11% (n=184)**	**86.49% (n=160)**	**72.86% (n=733)**
Mother tongue	Afrikaans	0.62% (n=2)	0.00% (n=0)	0.00% (n=0)	1.62% (n=3)	0.50% (n=5)
	English	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.54% (n=1)	0.10% (n=1)
	Sotho	1.54% (n=5)	17.14% (n=36)	6.97% (n=20)	**52.97% (n=98)**	15.81% (n=159)
	Tswana	0.00% (n=0)	**39.52% (n=83)**	**80.14% (n=230)**	20.54% (n=38)	34.89% (n=351)
	Xhosa	6.48% (n=21)	1.90% (n=4)	5.57% (n=16)	1.08% (n=2)	4.27% (n=43)
	Zulu	**91.05% (n=295)**	19.52% (n=41)	4.53% (n=13)	2.70% (n=5)	35.19% (n=354)
	Other	0.31% (n=1)	21.90% (n=46)	2.79% (n=8)	20.54% (n=38)	9.24% (n=93)
Relationship	M: LT*	28.57% (n=56)	19.53% (n=25)	24.83% (n=37)	33.94% (n=37)	26.63% (n=155)
	M: LA*	7.14% (n=14)	3.13% (n=4)	3.36% (n=5)	3.67% (n=4)	4.64% (n=27)
	UM: LT*	21.43% (n=42)	35.94% (n=46)	**37.58% (n=56)**	**34.86% (n=38)**	31.27% (n=182)
	UM: LA*	**42.86% (n=84)**	**41.41% (n=53)**	34.23% (n=51)	27.52% (n=30)	**37.46% (n=218)**

* M = married, LT = live together, LA = live apart, UM = unmarried

Respondents had similar profiles regarding the gender, age, religion and relationship status across projects. The mother tongue profile varied. The findings are discussed below.

Gender: The majority of respondents were female (70.58%, n=710). In the general South African population females represent fifty-one percent of the population among the nearly fifty million people resident in the country

(Statistics South Africa, 2010: 3). When looking at the representation of females among people infected with the HI virus in SSA, the scale tips to approximately 60% females (United Nations Program on HIV/AIDS , 2009: 22). UNAIDS (2009:22) explain that women's vulnerability to HIV in SSA stems not only from their greater physiological susceptibility to heterosexual transmission, but also to the severe social, legal and economic disadvantages they confront. Becoming infected is especially disproportionate for girls and young women. At 70.58% females, the ART patients in the SACBC ART projects therefore consist of a far higher percentage of women than expected. The lower number of males compared to females might be partly explained by the lower health seeking behavior among males (Wood, 2008: 393).

Age: The ages of the respondents varied from 18 to 77 years of age. There were no patients younger than 18 because of exclusion criteria of the study.

Religion: The projects under review are implemented by the AIDS Office of the SACBC, responsible for the coordination of HIV & AIDS-related projects in the Catholic Church. The projects do not exclusively serve Catholic patients. It is apparent that the majority of the patients reached by the projects under review are not Catholic (72.86%, n=733 non-Catholics). In the general South African population, Catholics represent around seven percent of the population (CIA, 2008: online), less than the percentage (27.14%, n=273) of Catholic respondents.

Mother tongue: South Africa has eleven official languages representing a diverse population (CIA, 2008: online). As expected, the respondents in the St Apollinaris model have a majority of Zulu speakers (91.05%, n=295), because the respondents live in rural KZN in an enclosed area. The Tapologo respondents mainly speak Tswana (80.14%, n=235); this is because the majority of the people in the area are from the Bafokeng tribe. Migrant labor does play a role here as 19.86% (n=57) of the respondents reported a mother tongue other than Tswana.

Hope for Life is situated in the former “Bophuthatswana homeland” and represents people from various language groups. The largest language group is Tswana (39.52%, n=83), but a large number of people reported languages other (21.90%, n=46) than the main language groups in the country, indicating some foreigners in the area. Bela-Bela displayed an even more diverse group of people with the largest group speaking Sotho (52.97%, n=98). The large number of languages other than the main language groups (20.54%, n=38) can be attributed to the satellite site in a nearby Ovambu tribe, originally from Namibia. In general the vast majority of people speaking a language reflected as “other” was represented by Sepedi (North Sotho) speakers.

Relationship status of respondents: The relationship status and whether the respondent lives with the partner was determined as one of many indicators of social support. UNAIDS (2009: 22) reported that single individuals (especially individuals who were recently divorced, separated or widowed) tend to have significantly higher HIV prevalence than those who had no partner, were married or cohabiting. The majority (57.90%, n=337) of the respondents reported they were living with a partner (26.63%, n=155 married to the partner and 31.27%, n=182 not married to the partner). A large proportion (42.15%, n=424) were not in a relationship.

Migration is an important demographic process shaping the age structure and distribution of the provincial population (Statistics South Africa, 2010: 3).

4.6.2. Migration

During the period between 2006 and 2011 Statistics South Africa (2010: 3) estimated that 211, 600 people migrated from the Eastern Cape to the rest of the country. Limpopo experienced an estimated net out-migration of over 140, 000 people. During the same period Gauteng and the Western Cape experienced an estimated net inflow of 364, 400 and 94, 600 migrants respectively.

Migration is not a risk factor for HIV, but the circumstances associated with people migrating between areas increase their vulnerability to HIV. USAID (2009:36) found that Tanzanian women who travelled away from home more than five times a year were twice as likely to become HIV-infected as those who did not travel. These findings were reported to be in line with earlier studies reported on by the United States Agency for International Development (USAID) where migrants were more likely than non-migrants to engage in high-risk or commercial sex, significantly increasing the migrants' vulnerability to HIV-infection.

Table 4.9 summarizes the data related to migration of the respondents. The movement of respondents seems to be between provinces more than between countries as only 2.19% (n=22) of the respondents reported that they originated from outside South Africa.

Table 4.9 **Migration**

Indicator		**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Country of birth	Other	0.31% (n=1)	0.95% (n=2)	2.79% (n=8)	5.95% (n=11)	2.19% (n=22)
	SA	**99.69% (n=323)**	**99.05% (n=208)**	**97.21% (n=279)**	**94.05%(n=174)**	**97.81% (n=984)**
Time lived in area	Minimum	4 months	3 months	3 months	12 months	3 months
	Median	31 years 9 months	25 years	21 years	25 years	28 years
	Maximum	65 years	77 years	64 years	74 years	77 years
Travelled away	< week	75.93% (n=246)	85.71 (n=180)	74.48% (n=213)	76.22% (n=141)	77.61% (n=780)
	> week	24.07% (n=78)	14.29% (n=30)	25.52% (n=73)	23.78% (n=44)	22.39% (n=225)
Weeks away	Minimum	0	1	1	1	0
	Median	4	3	3	15	4
	Maximum	**52**	**52**	**52**	40	52

Table 4.9 further highlights that the median duration for people living in the area where treatment was obtained, was in excess of 21 years. Furthermore, more than three quarters (77.61%, n=780) of the respondents live in the area full time as they indicated that they had not left the area for more than a week during the previous 12 months. The responses of 225 (22.39%) respondents who indicated that they had travelled from the area for more than a week during the last 12 months varied between projects. Three of the projects (St Apollinaris, Hope for Life and Tapologo) had patients who were away from the area the entire year – this might indicate that respondents work away from the area and travel back for treatment. The Bela-Bela respondents were away from the area for longer times (median = 14 weeks a year), but it seemed that all patients lived in the area at least 12 weeks a year (maximum = 40 weeks a year).

4.6.3. Environmental and psychosocial factors

De Haan (2005: 4-8) notes that, apart from appropriate health services (discussed in Chapter Five), environmental and psychosocial factors also play a vital role in the health of a population. Environmental factors include among others pollution, overcrowding, rapid urbanization, informal settlements, etc. Psychosocial factors include socio-economic, cultural and educational factors, and social welfare.

Environmental and psychosocial factors that influence the respondents will be discussed in this section. Where available the respondents will be compared with their counterparts in the same local municipality/district where they receive treatment. For this comparison the 2007 Community Survey conducted by Statistics South Africa will be used. The time frame is applicable as the fieldwork was done during the same period.

The above mentioned factors form part of the South African Bill of Rights (South Africa, 1996) which aims to protect the most vulnerable. The Bill of Rights forms an integral part of the South African Constitution. It states that it enshrines the rights of all people in the country and affirms the democratic values of human dignity, equality and freedom. It further binds the state to “respect, protect, promote and fulfill the rights in the Bill of Rights”. Where applicable the Bill of Rights will be discussed.

4.6.4. Socio-economic factors

Low socio-economic status is associated with disease, disability and death (De Haan, 2005: 6). An increased number of people in SSA are unemployed and the number living in poverty is increasing (Bradshaw and Steyn, 2001: 15). Rapid urbanization follows and a large number of people end up in informal settlements near urban areas (as seen at Tapologo and Hope for Life). The majority of informal settlements do not provide access to basic services.

From the results of participatory poverty assessments in South Africa, Statistics South Africa (2007e: 29) suggests that local communities view poverty not only as lacking or being deficient in income, but also as being isolated, having inadequate education and health services, lacking water supply, and lacking the ability to participate in the economic and social life of the community.

Given the importance of these factors in the health status of people, the next section will describe housing, water, sanitation, energy resources, education, employment, social welfare, food security, access to assets and alcohol use.

4.6.5. Housing

Statistics South Africa (2007e: 29) explains that “the characteristics of the dwellings in which households live and their access to various services and facilities provide an important indication of the well-being of household members," as shelter satisfies a basic human need for physical security and comfort.

The Bill of Rights (South Africa, 1996: 5) declares that "everyone has the right to have access to adequate housing." The new democracy started with a large backlog of houses (1.5 million people were living in informal settlements) according to the 1996 census (Statistics South Africa, 2004: 78). In 2007 Statistics South Africa (2007h: 10) reported that housing conditions were an important policy goal of the SAG, because of the impact on the socio-economic welfare of the population. Figure 4.10 reflects the main type of dwelling the respondents live in, in comparison to the main type of dwellings their counterparts live in, in their respective municipalities. Only the categories available for the municipality was recorded.

Table 4.10 **Main type of dwelling**

Indicator		St Apollinaris (Ingwe)	Hope for Life (Tshwane)	Tapologo (Rustenburg)	Bela-Bela (Bela-Bela)
Brick structure	Project		56.67% (n=119) [49.9;63.2]	47.74% (n=137) [42.0;53.5]	48.65% (n=90) [41.5;55.8]
	Municipality		53.80%	42.00%	53.40%
Traditional dwelling	Project	**69.14% (n=224) [63.9;73.9]**			
	Municipality	**83.30%**			
Informal (backyard)	Project			24.04% (n=69) [19.5;29.3]	**19.46% (n=36) [14.4;25.8]**
	Municipality			21.00%	**12.40%**
Informal (camp)	Project			**26.13% (n=75) [21.4;31.5]**	**26.49% (n=49) [20.7;33.3]**
	Municipality			**16.30%**	**9.90%**

Ingwe: (Statistics South Africa, 2007a: 164), Tshwane: (Statistics South Africa, 2007a: 102), Rustenburg: (Statistics South Africa, 2007a: 277), Bela-Bela: (Statistics South Africa, 2007a: 197).

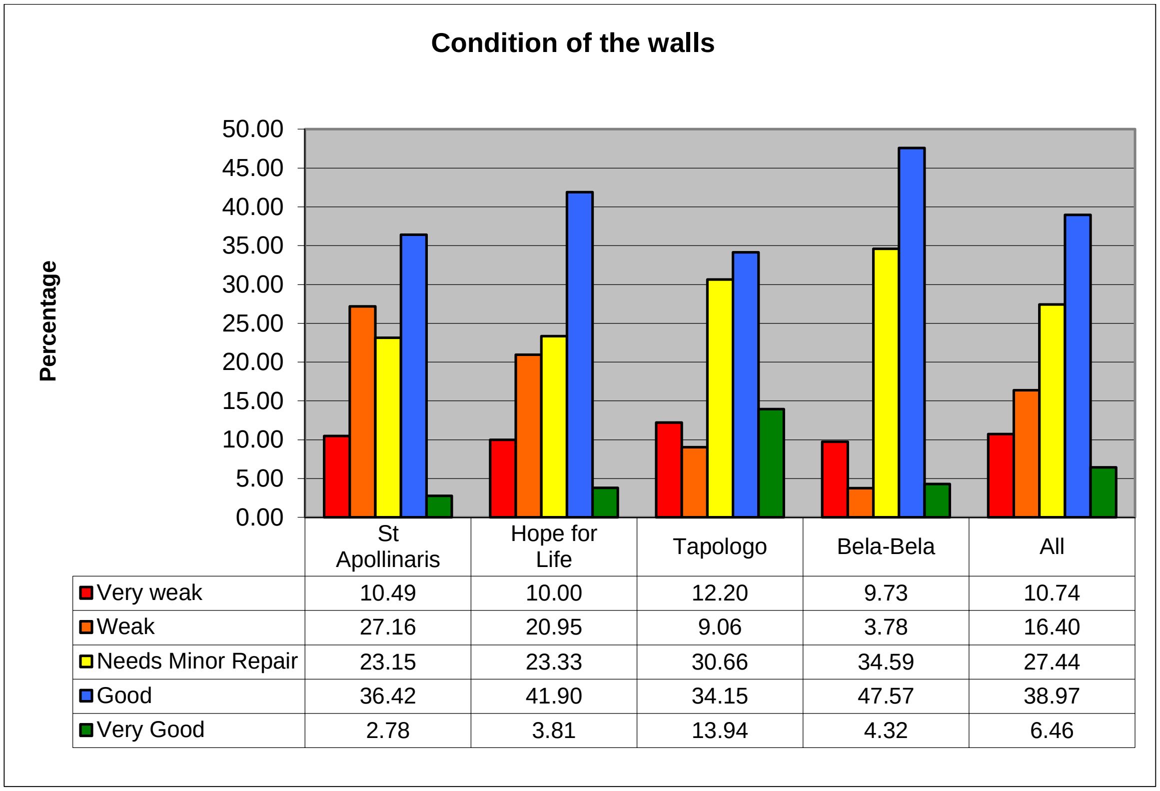
A big difference in type of dwelling for the respondents and the general population of the municipality was found at St Apollinaris. Fewer respondents lived in traditional dwellings. There was no difference found at Hope for Life. At Tapologo more respondents lived in informal dwellings in camps. Respondents at Bela-Bela were more likely to live in informal dwellings (in backyards and camps) than the general population.

The materials the walls and roof are made to coincide with the type of dwelling. Figure 4.11 reflects that at St Apollinaris traditional materials were used and at the other projects the majority of houses were made of bricks with a zinc roof. Only the main categories were recorded.

Table 4.11 Materials the walls and roof are made of

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Walls	Brick	15.74% (n=51)	**56.67% (n=119)**	**47.04% (n=135)**	**55.68% (n=103)**	**40.56% (n=408)**
	Zinc	0.62% (n=2)	28.10% (n=59)	46.49% (n=134)	37.30%(n=69	26.24% (n=264)
	Mud	**67.90% (n=220)**	9.05% (n=19)	0.35% (n=1)	0.00%(n=0)	23.86%(n=240)
Roof	Zinc	**43.83% (n=142)**	**90.00% (n=189)**	**91.29% (n=262)**	**94.56%(n=175)**	**76.34% (n=768)**
	Thatching	**46.91% (n=152)**	0.00%(n=0)	0.00%(n=0)	0.00%(n=0)	15.11% (n=152)

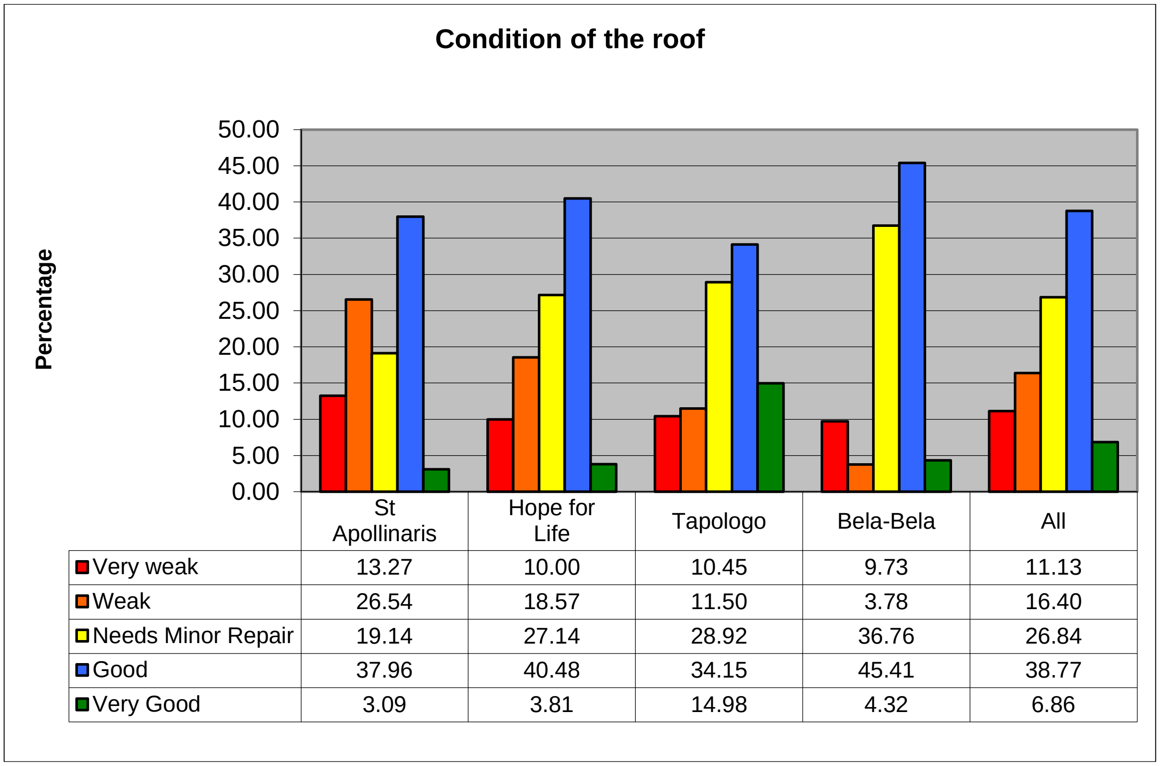
For the house to provide adequate shelter it should be in a good condition.



	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
🟥 Very weak	10.49	10.00	12.20	9.73	10.74
🟧 Weak	27.16	20.95	9.06	3.78	16.40
🟨 Needs Minor Repair	23.15	23.33	30.66	34.59	27.44
🟦 Good	36.42	41.90	34.15	47.57	38.97
🟩 Very Good	2.78	3.81	13.94	4.32	6.46

Figure 4.7 Condition of the walls.

Figures 4.2 and 4.3 reflect the condition of the walls and roofs of the respondents' dwellings. The condition of the walls and roofs of dwellings for the respondents at St Apollinaris and Hope for Life is weaker than those at Tapologo and Bela-Bela.



	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
🟥 Very weak	13.27	10.00	10.45	9.73	11.13
🟧 Weak	26.54	18.57	11.50	3.78	16.40
🟨 Needs Minor Repair	19.14	27.14	28.92	36.76	26.84
🟦 Good	37.96	40.48	34.15	45.41	38.77
🟩 Very Good	3.09	3.81	14.98	4.32	6.86

Figure 4.8 Condition of the roof.

Clean water and sanitation is crucial for good health (Statistics South Africa, 2007 e: 36; De Haan, 2005: 189).

4.6.6. Water and sanitation

With the dawn of democracy in 1994 the newly elected SAG inherited a backlog regarding the provision of clean safe water to 14 million people, and regarding access to adequate sanitation to 21 million people (De Haan, 2005: 188). By 2001 the Department of Water Affairs and Forestry had published their White Paper on Basic Household Sanitation and has ever since striven to eliminate the sanitation backlog. In this White Paper the Department acknowledges the need for clean water and adequate sanitation for all households in South Africa (South Africa. Department of Water Affairs and Forestry, 2001: 7). By 2007 Statistics South Africa (2007d: 34) reported that the access to piped water had increased significantly since the publication of the White Paper. The national average percentages per water source were: piped water in dwelling, 40.0%; piped water on-site, 31.3%; piped water at communal point, 15.8%; and stream, 3.6% (Statistics South Africa, 2007e: 40).

Regardless of the above mentioned improvement, most people living in the rural areas of South Africa still lack water and sanitation. Where these conditions are found together with contaminated water supplies, gastro-intestinal infections, such as cholera, dysentery, typhoid and infective hepatitis become a major community health problem that is responsible for a large proportion of the infant and child deaths in such areas (De Haan, 2005: 199).

Environmental hygiene and the influence of adequate sanitation on the environment are key to the prevention of many diseases and important to preserve natural resources like water (Statistics South Africa, 2007e: 37). On average 8.3% of South African households still do not have access to a toilet (Statistics South Africa, 2007e: 36). The Department of Water Affairs and Forestry set out to provide all South Africans with access to a basic minimum level of sanitation by 2010, a goal that was not reached (South Africa. Department of Water Affairs and Forestry, 2001: 18). By 2007 all the relevant districts still had households using bucket toilets and people living without access to any sanitation.

Table 4.12 tabulates the main source of water available to respondents compared to their municipal counterparts. Only the categories where data was available for the municipality was recorded. St Apollinaris was the only area relying heavily on water from a stream. This is due to the rural nature of the area. In comparison to the general population of the municipality, respondents at St Apollinaris used less piped water in the dwelling or water from the stream and more communal piped water. Hope for Life, Tapologo and Bela-Bela respondents used far less piped water in the dwelling and more piped water in the yard.

Table 4.12 Main type of water supply

Indicator		St Apollinaris (Ingwe)	Hope for Life (Tshwane)	Tapologo (Rustenburg)	Bela-Bela (Bela-Bela)
Piped (dwelling)	Project	**2.16% (n=7) [1.1;4.4]**	**12.86% (n=27) [9.0;18.1]**	**11.50% (n=33) [8.3;15.7]**	**7.03% (n=13) [4.2;11.7]**
	Municipality	**10.6%**	**62.5%**	**37.4%**	**62.4%**
Piped (on-site)	Project	17.59% (n=57) [13.8;22.1]	**60.00% (n=126) [53.3;66.4]**	**67.60% (n=194) [62.0;72.7]**	**75.68% (n=140) [69.0;81.3]**
	Municipality	17.2%	**18.2%**	**40.7%**	**17.2%**
Piped (Communal)	Project	**20.99% (n=68) [16.9;25.7]**	16.67% (n=35) [12.2;22.3]	5.57% (n=16) [3.5;8.9]	10.81% (n=20) [7.1;16.1]
	Municipality	**9.5%**	16.4%	8.5%	7.5%
Stream	Project	**28.70% (n=93) [24.0;33.9]**			
	Municipality	**49.5%**			

Ingwe: (Statistics South Africa, 2007a: 164; 2007g: 15), Tshwane: (Statistics South Africa, 2007a: 102; 2007f: 12), Rustenburg: (Statistics South Africa, 2007a: 277; 2007i: 13), Bela-Bela: (Statistics South Africa, 2007a: 197; 2007h: 15).

Table 4.13 indicates that the majority of respondents at St Apollinaris, Hope for Life and Tapologo made use of pit latrines, while the majority of respondents at Bela-Bela made use of flush toilets. St Apollinaris respondents reported using more pit latrines, with very few respondents not having a toilet. Respondents at Hope for Life and Tapologo used more pit latrines and fewer flush toilets while Bela-Bela respondents used slightly fewer flush toilets than the general population in the municipality. Only the categories where data was available for the municipality was recorded.

Table 4.13 **Main type of toilet**

Indicator		**St Apollinaris (Ingwe)**	**Hope for Life (Tshwane)**	**Tapologo (Rustenburg)**	**Bela-Bela (Bela-Bela)**
Flush	Project		**34.76% (n=73) [28.6;41.4]**	**23.7% (n=68) [19.1;28.9]**	**68.65% (n=127) [61.6;74.9]**
	Municipality		**71.3%**	**51.5%**	**76.6%**
Pit latrine	Project	**96.61% (n=313) [94.0;98.1]**	**65.24% (n=137) [58.6;71.4]**	**55.41% (n=159) [49.6;61.0]**	24.86% (n=46) [19.2;13.6]
	Municipality	**54.1%**	**21.1%**	**37.1%**	13.2%
No toilet	Project	**0.62% (n=2) [0.2;2.2]**	0.00% (n=0) [0;1.8]	3.83% (n=11) [2.2;6.7]	0.54% (n=1) [0.1;3.0]
	Municipality	**6.6%**	1.4%	5.7%	1.4%

Ingwe: (Statistics South Africa, 2007a: 164; 2007d: 77; 2007g: 21), Tshwane: (Statistics South Africa, 2007a: 102; 2007d: 75; 2007f: 13), Rustenburg: (Statistics South Africa, 2007a: 277; 2007d: 80; 2007i: 14), Bela-Bela: (Statistics South Africa, 2007a: 197; 2007d: 80; 2007h: 16)

4.6.7. Main source of energy used by the respondents

The availability of electricity for lighting, heating and cooking can be used as benchmark of what is available to respondents and their counterparts in the relevant municipalities. From Table 4.14 it is evident that Ingwe municipality has least access to electricity as a source of energy among the four municipalities. Only the main categories were recorded.

Table 4.14 **Electricity available to household by municipality**

District	**Lighting**	**Cooking**	**Heating**	**Statistics South Africa:**
Ingwe	**34,8%**	**9,9%**	**8,0%**	(2007d: 65)
Tshwane	77,4%	74,1%	70,2%	(2007d: 63)
Rustenburg	77,7%	71,0%	68,9%	(2007d: 68)
Bela-Bela	79,1%	61,6%	48,5%	(2007d: 66)

The main source of energy used for lighting is tabulated in Table 4.15. In line with the lack of availability of electricity in the Ingwe municipality, people used candles as the main source, while the other areas used electricity. Only

Tapologo respondents' energy usage patterns were different from their counterparts'. Tapologo respondents use slightly more candles that the rest of the population in the municipality. Only the categories where data was available for the municipality was recorded.

Table 4.15 Main source of energy used for lighting

Indicator		St Apollinaris (Ingwe)	Hope for Life (Tshwane)	Tapologo (Rustenburg)	Bela-Bela (Bela-Bela)
Electricity	Project	35.80% (n=116) [30.8;41.2]	74.29% (n=156) [68.0;79.7]	75.61% (n=217) [70.3;80.2]	75.68% (n=140) [69.0;81.3]
	Municipality	34.8%	77.4%	77.7%	79.1%
Candles	Project	62.65% (n=203) [57.3;67.7]		**19.51% (n=56)** **[15.3;24.5]**	22.16% (n=41) [16.8;28.7]
	Municipality	61.5%		**13.6%**	17.8%

Ingwe: (Statistics South Africa, 2007a: 164; 2007g: 17), Tshwane: (Statistics South Africa, 2007a: 102; 2007f: 11), Rustenburg: (Statistics South Africa, 2007a: 277; 2007i: 12), Bela-Bela: (Statistics South Africa, 2007a: 197; 2007h: 13;)

Table 4.16 tabulates the main source of energy used for cooking. Only the categories where data was available for the municipality was recorded. People in Ingwe used wood as main source, while the other areas used electricity and paraffin. The people in Ingwe will have access to wood due to the large pine plantations in the area. The more urban areas will have access to electricity and paraffin. Differences between the respondents and the municipality's population can be seen at St Apollinaris, Hope for Life and Bela-Bela. St Apollinaris respondents used less wood, Hope for Life respondents use less electricity and Bela-Bela respondents use more paraffin.

Table 4.16 Main source of energy used for cooking

Indicator		St Apollinaris (Ingwe)	Hope for Life (Tshwane)	Tapologo (Rustenburg)	Bela-Bela (Bela-Bela)
Electricity	Project	11.73% (n=38) [8.7;15.7]	**61.43% (n=129)** **[54.7;67.8]**	66.9% (n=192) [61.3;72.1]	54.59% (n=101) [47.4;61.6]
	Municipality	9.9%	**74.1%**	71.0%	61.6%
Wood	Project	**76.85% (n=249)** **[72.0;81.1]**		2.79% (n=8) [1.4;5.4]	7.03% (n=13) [4.2;11.7]
	Municipality	**82.0%**		1.5%	7.8%
Paraffin	Project	6.17% (n=20) [4.0;9.3]	**35.24% (n=74)** **[29.1;41.9]**	29.27% (n=84) [24.3;34.8]	**34.59% (n=64)** **[28.1;41.7]**
	Municipality	5.2%	**24.1%**	26.0%	**27.5%**

Ingwe: (Statistics South Africa, 2007a: 164; 2007g: 17), Tshwane: (Statistics South Africa, 2007a: 102; 2007f: 11), Rustenburg: (Statistics South Africa, 2007a: 277; 2007i: 12), Bela-Bela: (Statistics South Africa, 2007a: 197; 2007h: 13)

The respondents from Hope for Life, Tapologo and Bela-Bela did not all indicate a main source as these areas do not have such extreme winters as seen in Table 4.17. Energy use would therefore rather be for cooking that for heating. Only the categories where data was available for the municipality was recorded.

Table 4.17 Main source of energy used for heating

Indicator		St Apollinaris (Ingwe)	Hope for Life (Tshwane)	Tapologo (Rustenburg)	Bela-Bela (Bela-Bela)
Electricity	Project	**4.03% (n=13)** **[2.4;6.8]**	**30.0% (n=63)** **[24.2;36.5]**	**25.44% (n=73)** **[20.7;30.8]**	**9.73% (n=18)** **[6.2;14.9]**
	Municipality	**8.0%**	**70.2%**	**68.9%**	**48.5%**
Wood	Project	85.45% (n=276) [81.2;88.9]		**11.15% (n=32)** **[8.0;15.3]**	**7.03% (n=13)** **[4.2;11.7]**
	Municipality	85.2%		**6.2%**	**22.8%**
Paraffin	Project	3.72% (n=12) [2.1;6.4]	**9.05% (n=19)** **[5.9;13.7]**	**3.83% (n=11)** **[2.2;6.7]**	**1.62% (n=3)** **[0.6;4.7]**
	Municipality	4.0%	**18.6%**	**21.6%**	**9.8%**

Ingwe: (Statistics South Africa, 2007a: 164; 2007g: 17), Tshwane: (Statistics South Africa, 2007a: 102; 2007f: 11), Rustenburg: (Statistics South Africa, 2007a: 277; 2007i: 12), Bela-Bela: (Statistics South Africa, 2007a: 197; 2007h: 13)

Respondents at St Apollinaris used less electricity for heating than their municipality counterparts. Hope for Life respondents used less electricity and paraffin than the rest of the residents of the municipality. At Tapologo respondents reported more electricity and wood, and less paraffin use. Bela-Bela respondents used less energy overall (electricity, wood and paraffin).

4.6.8. Education and employment

The link between poverty and education is well known, so is their combined impact on health (De Haan, 2005: 8). In a strategy on education and poverty reduction, the Human Sciences Research Council describes that the lack of education is one of the most powerful determinants of poverty, while unequal access to education is strongly associated with poverty (Maile, 2008: 53). Statistics South Africa (2007e: 8) states that education is a vehicle for empowerment, economic growth and general improvement in welfare. In South Africa the right to basic education is protected by the South African Bill of Rights, as part of the National Constitution (South Africa, 1996: 16).

Statistics South Africa (2007b: 30) reported in 2007 that more than 10.0% of the population did not have any formal schooling. In the age group older than 20 years, 40.1% completed some secondary school while only 28.0% completed grade 12 (Statistics South Africa, 2007c: 2). Only 9.1% of the population completed tertiary education (Statistics South Africa, 2007b: 30).

Respondents obtained far fewer educational achievements that the national average as seen in Table 4.18.

Data on the levels of schooling completed are currently the best available indicator of the level of skills available in the labor force and the employability of workers (Statistics South Africa, 2007e: 10). The General Household Survey (Statistics South Africa, 2007e: 22-24) and the Labor Force Survey (Statistics South Africa, 2007j: ii) reported the unemployment rate at 24.8% and 25.5% respectively. The respondents reported an unemployment rate in excess of 80.0%.

Fewer than one in five respondents is employed, while more than one out of two respondents see themselves as the breadwinner in their home. With such a large percentage of the breadwinners being unemployed the question beckons to the source of income.

Table 4.18 Education, employment and household income

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Highest educational level completed	No school	7.10% (n=23)	8.10% (n=17)	6.27% (n=18)	12.97% (n=24)	8.15% (n=82)
	Some school	**84.87%** **(n=275)**	**76.20%** **(n=160)**	**80.49%** **(n=231)**	**87.24%** **(n=142)**	**80.33%** **(n=808)**
	Grade 12	7.72% (n=25)	14.29% (n=30)	13.24% (n=38)	8.65% (n=16)	10.83% (n=109)
	Tertiary	0.31% (n=1)	1.43% (n=3)	0.00% (n=0)	1.62% (n=3)	0.70% (n=7)
Employed		14.51% (n=47)	14.29% (n=30)	16.72% (n=48)	17.84% (n=33)	15.71% (n=158)
Breadwinner		53.09% (n=172)	65.24% (n=137)	55.40% (n=159)	65.41% (n=121)	58.55% (n=589)
Source of income	Salaries	10.80% (n=35)	12.86% (n=27)	23.00% (n=66)	24.32% (n=45)	17.20% (n=173)
	Wages	9.26% (n=30)	8.10% (n=17)	6.97% (n=20)	3.78% (n=7)	7.26% (n=74)
	Remittance	8.33% (n=27)	2.86% (n=6)	9.76% (n=28)	13.51% (n=25)	8.55% (n=86)
	Grants	**66.05%** **(n=214)**	**68.10%** **(n=143)**	**40.07%** **(n=115)**	**38.38%** **(n=71)**	**53.98%** **(n=543)**
	Informal trade	2.78% (n=9)	4.76% (n=10)	5.92% (n=17)	7.02% (n=13)	4.87% (n=49)
	No income	2.78% (n=9)	3.33% (n=7)	14.29% (n=41)	12.97% (n=24)	8.05% (n=81)

The respondents' main source of income is social grants. Statistics South Africa (2007e: 27) reports that the majority of households in which people are not employed rely on financial assistance from a person within their household

(77.5%), a person outside the household (14.9%), and social grants (10.25%). All the projects had higher reliance on social grants than is the case in the general population.

4.6.9. Social welfare

According to Statistics South Africa (2007e: 48) social security grants were the most direct form of wealth transfer to poor households in 2006. Expenditure has increased four times since the start of democracy. The bill was already in excess of R70 billion a year. Government grants available to the public are foster care grants, care dependency grants, war veterans' grants, old age grants, disability grants and child support grants.

Figure 4.19 paints a bleak picture of grant dependency with the large numbers of respondents (79.03%, n=795) who have applied for a social grant. The majority of respondents were accessing disability grants - a grant available to those with a CD4 count below 200 cells/mm^3. This will, however, change as respondents use ART and their CD4 counts increase. The fear of losing their main source of income (the grant) can cause serious adherence problems. The respondents were also asked the status of their application. The majority (62.14%, n=494) was still receiving grants.

Respondents were asked if their family members (from the same household) also receive a grant. At St Apollinaris 95 (29.32%) family members received disability grants and 67 (20.68%) received child support grants. Respondents at Hope for Life reported that 42 (20.0%) of family members received disability grants and 31 (14.76%) child support grants. At Tapologo, 63 (21.95%) family members received disability grants and 48 (16.72%) child support grants. Slightly fewer family members at Bela-Bela were reported as receiving grants. Thirty one (16.76%) received disability grants while 21 (11.35%) received child support grants. This confirms that the respondents were the main “breadwinners” through receiving disability grants (see Table 4.18).

Table 4.19 Social welfare (grants) received

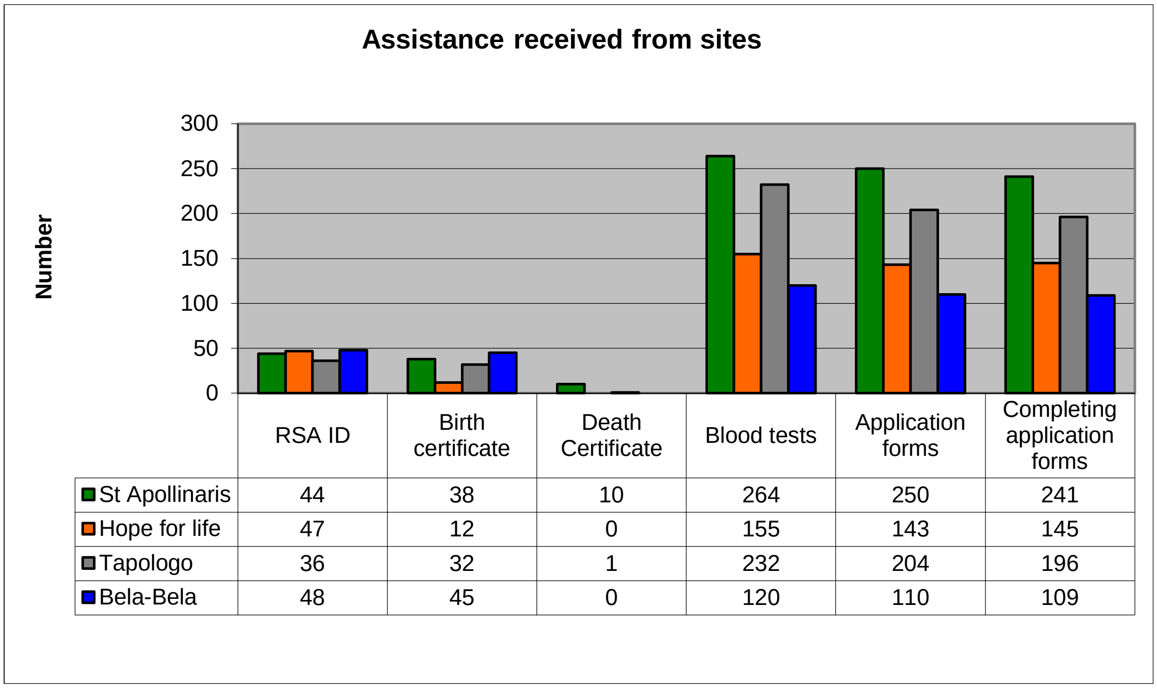
Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Grant	Disability	**97.14% (n=170)**	**97.33% (n=146)**	**98.21% (n=110)**	**96.49% (n=55)**	**97.37% (n=481)**
	Old age	1.71% (n=3)	2.67% (n=4)	0.89% (n=2)	3.51% (n=2)	2.02% (n=10)
Ever applied for grant		88.58% (n=287)	85.24% (n=179)	74.91% (n=215)	61.62% (n=114)	79.03% (n=795)
Status	Receiving	**60.98% (n=175)**	**83.80% (n=150)**	**52.09% (n=112)**	**50.00% (n=57)**	**62.14% (n=494)**
	Submitted	14.63% (n=42)	5.49% (n=10)	21.86% (n=47)	11.40% (n=13)	14.09% (n=112)
	Refused	10.10% (n=29)	2.23% (n=4)	13.02% (n=28)	15.79% (n=18)	9.94% (n=79)
	Stopped	11.85% (n=34)	6.15% (n=11)	4.19% (n=9)	21.93% (n=25)	9.94% (n=79)
	Not paid yet	2.09% (n=6)	1.68% (n=3)	3.26% (n=7)	0.88% (n=1)	2.14% (n=17)
	Not applied	0.00% (n=0)	0.56% (n=1)	5.58% (n=12)	0.00% (n=0)	1.64% (n=13)

Table 4.20 tabulates the reasons why some (9.94%, n=79) respondents were refused a grant and why others’ (9.94%, n=79) grants were stopped. Nearly half of the respondents responded that their health improved (49.37%, n=39 and 59.49%, n=47). It is, however, concerning that large numbers of the respondents (43.43%, n=34 and 31.64%, n=25) did not understand why their grant applications were refused or their grants stopped.

Table 4.20 Grants refused or stopped

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Refusal	CD4 above 200 cells/mm^3	24.14% (n=7)	0.00% (n=0)	67.86% (n=19)	72.22% (n=13)	49.37% (n=39)
	Unknown to respondent	68.96% (n=20)	75.00% (n=3)	21.42% (n=6)	27.78% (n=5)	43.43% (n=34)
Stopped	CD4 above 200 cells/mm^3	58.82% (n=20)	36.36% (n=4)	55.56% (n=5)	72.00% (n=18)	59.49% (n=47)
	Unknown to respondent	26.47% (n=9)	45.45 (n=5)	44.44% (n=4)	28.00% (n=7)	31.64% (n=25)

One of the many services provided to respondents by the projects is assistance with accessing social grants. Respondents were asked if the project had assisted them with the application process. Figure 4.4 highlights the number of respondents who had received assistance to obtain social grants. Respondents could indicate more than one option under assistance.



	RSA ID	Birth certificate	Death Certificate	Blood tests	Application forms	Completing application forms
🟩 St Apollinaris	44	38	10	264	250	241
🟧 Hope for life	47	12	0	155	143	145
▨ Tapologo	36	32	1	232	204	196
🟦 Bela-Bela	48	45	0	120	110	109

Figure 4.9 Assistance provided by projects to obtain social grants

4.6.10. Food security

The conventional measure of hunger is usually to regard consumption of less than 1960 calories per day as “hunger” (Statistics South Africa, 2007e: 46). For simplicity’s sake the researcher will only indicate the respondents who indicated that they go hungry due to a lack of food, in line with the Statistics South Africa. Statistics South Africa (2007e: 46) only indicates the broad extent to which household members experience hunger as it is based on their own-perception of hunger. In general 2.0% of South Africans reported that they go hungry on a regular basis. Table 4.21 tabulates the response of respondents when asked if they go hungry due to a lack of food and if so, how often they go hungry.

Table 4.21 Respondents going hungry due to a lack of food

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Times going hungry	Daily	7.10% (n=23)	5.24% (n=11)	10.49% (n=30)	6.49% (n=12)	7.56% (n=76)
	Weekly	11.42% (n=37)	8.57% (n=18)	13.99% (n=40)	15.14% (n=28)	12.24% (n=123)
	Monthly	33.02% (n=107)	22.86% (n=48)	15.73% (n=45)	11.89% (n=22)	22.09% (n=222)
	Never	48.46% (n=157)	63.33% (n=133)	59.79% (n=171)	66.49% (n=123)	58.11% (n=584)
People in house	Minimum	0	0	0	0	0
	Median	5	3	3	4	4
	Maximum	24	12	14	13	24

Fewer respondents at St Apollinaris never go hungry (48.46%, n=157) than the respondents at the other projects. The size of the households at St Apollinaris was also larger than the households in the other projects.

4.6.11. Access to household assets

Statistics South Africa (2007e: 45) collects household asset information as an indicator of household wealth. The asset index is comparatively reliable in comparison with other property estimates (Bradshaw and Steyn, 2001: 35).

Statistics South Africa argues that the ownership of assets can help buffer the poor against adverse circumstances as assets such as houses, land and mobile assets can be sold. In the 2007 General Household Survey, Statistics South Africa (2007e: 44-45) focused on the ownership of television and radios as well as access to cell phones. Changes in the television and radio ownership were reported as a reflection of household wealth. The access to cell phones indicated the households' ability to communicate. The conclusion was made that the access to these assets could be used as a general indicator of an improvement in material wealth, as these trends correspond with other related economic activities and a decrease in hunger in households.

The access respondents had to a radio, cell phone, landline telephone, television, refrigerator and computer was compared to the access their municipal counterparts had. Table 4.22 summarizes the access to the above mentioned assets by project compared to the relevant municipality. St Apollinaris respondents had more access to 5/6 assets, while Hope for Life respondents had less access to 4/6 assets. Tapologo and Bela-Bela showed a mixed picture. Tapologo respondents had access to 2/6 more and 2/6 less than the municipality residents. At Bela-Bela respondents had 1/6 more and 2/6 less.

Table 4.22 Access to assets

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Radio	Access	**81.17% (n=263)** **[76.6;85.1]**	**64.29% (n=135)** **[57.6;70.5]**	64.81% (n=186) [59.1;70.1]	69.19% (n=128) [62.2;75.4]
	Municipality*	**68.70%**	**80.80%**	67.80%	74.60%
Cell phone	Access	**82.72% (n=268)** **[78.2;86.4]**	85.71% (n=180) [80.3;89.8]	74.56% (n=214) [69.2;79.3]	**73.51% (n=136)** **[66.7;79.3]**
	Municipality**	**60.20%**	83.30%	75.13%	**62.20%**
Landline	Access	4.01% (n=13) [2.4;6.7]	**7.62% (n=16)** **[4.7;12.0]**	**1.39% (n=4)** **[0.5;3.5]**	**5.41% (n=10)** **[3.0;9.7]**
	Municipality***	3.20%	**24.80%**	**6.80%**	**16.80%**
TV	Access	**39.20% (n=127)** **[34.0;44.6]**	78.57% (n=165) [72.5;83.6]	**63.41% (n=182)** **[57.7;68.8]**	69.73% (n=129) [62.8;75.9]
	Municipality****	**27.10%**	74.10%	**53.60%**	66.20%
Refrigerator	Access	**32.10% (n=104)** **[27.3;37.4]**	**63.81% (n=134)** **[57.1;70.0]**	**61.67% (n=177)** **[55.9;67.1]**	63.24% (n=117) [56.1;69.9]
	Municipality*****	**22.70%**	**70.80%**	**52.70%**	63.50%
Computer	Access	**0.62% (n=2)** **[0.2;2.2]**	**4.29% (n=9)** **[2.3;7.9]**	**4.18% (n=12)** **[2.4;7.2]**	**5.41% (n=10)** **[3.0;9.7]**
	Municipality******	**3.30%**	**28.60%**	**9.10%**	**11.10%**

* Ingwe: (Statistics South Africa, 2007g: 25); Tshwane: (Statistics South Africa, 2007f: 15); Rustenburg: (Statistics South Africa, 2007i: 17); Bela-Bela: (Statistics South Africa, 2007h: 19) ** Ingwe: (Statistics South Africa, 2007g: 24); Tshwane: (Statistics South Africa, 2007f: 15); Rustenburg: (Statistics South Africa, 2007i: 16); Bela-Bela: (Statistics South Africa, 2007h: 18) *** Ingwe: (Statistics South Africa, 2007g: 33); Tshwane: (Statistics South Africa, 2007f: 20); Rustenburg: (Statistics South Africa, 2007i: 22); Bela-Bela: (Statistics South Africa, 2007h: 24) **** Ingwe: (Statistics South Africa, 2007g: 31); Tshwane: (Statistics South Africa, 2007f: 19); Rustenburg: (Statistics South Africa, 2007i: 21); Bela-Bela: (Statistics South Africa, 2007h: 23) ***** Ingwe: (Statistics South Africa, 2007g: 30); Tshwane: (Statistics South Africa, 2007f: 18); Rustenburg: (Statistics South Africa, 2007i: 20); Bela-Bela: (Statistics South Africa, 2007h: 22) ****** Ingwe: (Statistics South Africa, 2007g: 27); Tshwane: (Statistics South Africa, 2007f: 16); Rustenburg: (Statistics South Africa, 2007i: 18); Bela-Bela: (Statistics South Africa, 2007h: 20)

Various levels of poverty exists among the respondents. De Haan (2005: 6) argues that the frustration of living in poor conditions leads to behavioral problems, such as alcohol abuse, which have a negative impact on the health of the individual and complicate the care of the patient (Swanson, 2010: 283).

4.6.12. Alcohol use

Alcohol abuse negatively impacts on adherence to ART (Mellins *et al*, 2009: 172; Legorreta *et al*, 2005: 945). Drug and alcohol interactions are also emerging as critically important factors influencing liver function. Liver dysfunctions might lead to harmful accumulation of some HIV drugs if doses are not adjusted properly as some ART is metabolized by the liver (Barve *et al*, 2010: 232). Barve *et al* (2010: 231) warn that HCWs do not adequately assess alcohol abuse in ART patients, although it is prevalent among them. Self-reported alcohol use among respondents is reflected in Table 4.23.

Table 4.23 Alcohol use

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Frequency	Never	**95.99% (n=311)**	**72.73% (n=152)**	**87.37% (n=249)**	**86.94% (n=160)**
	Once a month	3.09% (n=10)	14.83% (n=31)	7.72% (n=22)	9.19% (n=17)
	2-3 times a month	0.00% (n=0)	8.13% (n=17)	2.46% (n=7)	2.16% (n=4)
	1-2 a week	0.93% (n=3)	3.35% (n=7)	1.40% (n=4)	1.08% (n=2)
	3-4 a week	0.00% (n=0)	0.96% (n=2)	1.05% (n=3)	0.54% (n=1)
	Every day	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.54% (n=1)
Servings	Less than 3	**61.54% (n=8)**	**42.11% (n=24)**	**51.43% (n=18)**	**56.00% (n=14)**
	More than 3, less than 5	15.38% (n=2)	22.81% (n=13)	20.00% (n=7)	24.00% (n=6)
	More than 5, less than 7	7.69% (n=1)	12.28% (n=7)	14.29% (n=5)	4.00% (n=1)
	More than 7, less than 9	7.69% (n=1)	7.02% (n=4)	0.00% (n=0)	4.00% (n=1)
	More than 9, less than 11	0.00% (n=0)	5.26% (n=3)	8.57% (n=3)	4.00% (n=1)
	More than 12	7.69% (n=1)	10.53% (n=6)	5.71% (n=2)	8.00% (n=2)

The majority of the respondents indicated that they never used alcohol. Those who admitted to using alcohol seemed to be using alcohol once a month (may reflect occasional substance use). The majority of respondents took less than 5 servings of alcohol when they used alcohol. Although the incidence of alcohol use seems low, HCWs should ensure the topic is covered in counseling sessions.

4.7. Summary

Table 4.24 summarizes some of the main findings from Chapter four. It is clear that the St Apollinaris project is a traditional hospital-based project providing centralized ART services. The hospital started as a Mission hospital and retained the relationship with the Catholic Church after government take-over. Travel to the facility was a problem as the median travel time was nearly two hours and patients had to pay a median of R17 to reach the hospital. The hospital, however, benefited from hospital-based infrastructure, such as on-site 24-hour in-patient care as well as pharmacy and laboratory services. Services were provided five days a week between 8:00 and 16:30.

Hope for Life is a more traditional ART clinic-based project providing centralized ART services. The project consists of a group of Catholic community-based projects feeding into a centralized ART project. Travel was something of a problem with the median travel time of one hour at the median cost of R6 to reach the ART provision point. As the ART provision was centralized, patients had access to staff four days a week between 8:00 and 16:30. Pharmacy and laboratory services were sourced from central service providers based in Gauteng.

Tapologo is an organization that coordinates the HIV & AIDS response of the Diocese of Rustenburg. The project has a centralized administrative office, but services are provided at decentralized points of care. Travel was less of a problem as the median patient could reach the clinic within half an hour at no cost The mobile nature of the project, however, meant that patients only had access to the ART team once or twice a week between 8:00 and 16:30. Pharmacy and laboratory services were sourced from central service providers based in Gauteng.

Bela-Bela is an NGO-managed ART clinic that works in close cooperation with the SAG. The project is an independent NGO with a historical link to the Catholic Church. The project provided centralized ART provision with two outreach sites. Travel was not a major problem as the median patients could reach the clinic within half an hour at no cost. The project provided scheduled transport to the outreach site's patients. The patients had access to the ART staff five days a week between 8:00 and 16:30 with some appointments scheduled after hours. Pharmacy and laboratory services were sourced from central service providers based in Gauteng.

Table 4.24 Main findings on background and access to care

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Background	Mission hospital, now public district hospital	Catholic community projects working together	Catholic Community project providing different services	NGO providing HIV care and support in the community
Physical structure for ART provision	Pre-fabricated buildings (park homes)	Brick buildings	Informal structures (freight containers), old brick buildings	Pre-fabricated buildings (Wendy-houses)
ART provision	Centralized	Centralized	Decentralized	Centralized
ART provision at	Hospital	2 Clinics	All service points	Clinic
Administrative and logistic support	Centralized	Centralized	Centralized	Centralized
Community-based support	Limited	Yes	Yes	Yes
Relationship with SAG	Public facility, SAG-managed	Independent, NGO-managed	Independent, NGO-managed	Close relationship, NGO-managed
Median time travelled	1 hr., 52 min	1 hr.	½ hr.	½ hr.
Median cost of travel	R17.00	R6.00	0	0
Days ART service provided	Mon-Fri	Mon -Thu	1 day a month to 1 day a week	Mon-Fri
Operating hours on these days	8 hours	8 hours	8 hours	8 hours + (some after hour consultation)
24 hour in-patient care available	On-site (hospital)	No, seek help at SAG facility	Off-site (hospice)	No, seek help at on-site SAG facility
Pharmacy services	On-site, hospital-based	Centralized based in Gauteng	Centralized based in Gauteng	Centralized based in Gauteng
Laboratory services	On-site, hospital-based	Centralized based in Gauteng	Centralized based in Gauteng	Centralized based in Gauteng

hr. = hour, min = minutes

In order to establish if the most impoverished persons had access to the services offered by the projects, respondents were compared to their counterparts in the municipality they come from.

4.7.1. Comparing patient profiles to those of municipal counterparts

Certain indicators of the respondents' profile were compared to the 2007 (same time period as the study) Community and General Household Surveys conducted in South Africa by Statistics South Africa. A confidence interval of 95% for the prevalence was determined to establish if there is a difference between the respondents in the study and the general population of the municipality where treatment was accessed.

Compared to the population of Ingwe, respondents accessing ART at St Apollinaris had 5/7 indicators of being richer that their counterparts.

- ✓ Fewer traditional dwellings *(richer, traditional is the norm)*
- ✓ *Less piped water in the dwelling*, more piped communal water *(poorer)* and *less water at the stream* *(richer)*
- ✓ More pit latrines and fewer with no toilet *(richer)*
- ✓ Less wood for cooking *(richer, wood is free in the area)*
- ✓ *Less electricity for heating* *(poorer)*
- ✓ More access to radios, cell phones, TVs, refrigerators *(richer)*

Respondents accessing ART at Hope for Life, had 5/5 indicators that they were poorer than the rest of the population in the Tshwane Metropolitan.

- ✓ *Less piped water in the dwelling*, more piped water on-site *(poorer)*
- ✓ *Fewer flush toilets*, more pit latrines *(poorer)*
- ✓ *Less electricity* and more paraffin for cooking *(poorer)*

- ✓ *Less electricity and paraffin* for heating *(poorer)*
- ✓ *Less access to radios, land lines and refrigerators (poorer)*

Tapologo respondents accessing ART had 6/7 indicators indicating that they were poorer than the population of Rustenburg.

- ✓ *More informal dwellings (poorer)*
- ✓ *Less piped water in the dwelling and on-site (poorer)*
- ✓ *Fewer flush toilets* and more pit latrines *(poorer)*
- ✓ *More candles* for lighting *(poorer)*
- ✓ *Less electricity and paraffin* and more wood for heating *(poorer)*
- ✓ More access to TVs and refrigerators *(richer), less access to landlines (poorer)*

Respondents accessing ART at the Bela-Bela had 6/7 indicators that indicated they were poorer than the population of Bela-Bela.

- ✓ *More informal dwellings*, both in the backyard and the camps *(poorer)*
- ✓ *Less piped water in the dwelling*, more piped water on-site *(poorer)*
- ✓ *Fewer flush toilets* and more pit latrines *(poorer)*
- ✓ *More paraffin* for cooking *(poorer)*
- ✓ *Less electricity, wood and paraffin* for heating *(poorer)*
- ✓ More access to cell phones *(richer) and less access to land lines (poorer)*

From the data tabulated in Table 4.25 it appears that that respondents at St Apollinaris might be richer than their counterparts while at the other three projects provided access to the poorest of the poor.

Table 4.25 Respondents compared to their municipal counterparts

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Dwelling	Brick structure		Similar	Similar	Similar
	Traditional dwelling	*Less*			
	Informal (backyard)				More
	Informal (camp)			More	More
Water	Piped (in dwelling)	*Less*	*Less*	*Less*	*Less*
	Piped (on-site)	Similar	More	More	More
	Piped (communal)	More	Similar	Similar	Similar
	Stream	*Less*			
Toilet	Flush		*Less*	*Less*	*Less*
	Pit latrine	More	More	More	More
	No toilet	*Less*	Similar	Similar	Similar
Lighting	Electricity	Similar	Similar	Similar	Similar
	Candles	Similar		More	Similar
Cooking	Electricity	Similar	*Less*	Similar	Similar
	Wood	*Less*		Similar	Similar
	Paraffin	Similar	More	Similar	More
Heating	Electricity	*Less*	*Less*	*Less*	*Less*
	Wood	Similar		More	*Less*
	Paraffin	Similar	*Less*	*Less*	*Less*
Assets	Radio	More	*Less*	Similar	Similar
	Cell phone	More	Similar	Similar	*Less*
	Landline	Similar	*Less*	*Less*	*Less*
	TV	More	Similar	More	Similar
	Refrigerator	More	*Less*	More	Similar

Chapter Four contained aspects related to access to care and the respondents who managed to gain access to the four projects in this study, while Chapter Five will describe the continuum of care offered at the projects.

CHAPTER 5: CONTINUUM OF CARE

The clinical course of untreated HIV-infection has by now been established. In most cases HIV causes progressive loss of T-helper lymphocytes, which eventually renders the patient unable to mount an immune response against a variety of opportunistic pathogens (Mayer and Cohen, 2003: 708). T-helper lymphocyte counts in untreated individuals eventually decline to a point that clinical illness and death is imminent. With the introduction of ART, HIV became a chronic disease. HIV care thus needs to be provided within a continuum of care. The continuum of care starts when an individual is diagnosed. It includes (but is not limited to) prophylaxis, screening and treatment for OIs, counseling and support as well as ART. Individuals on ART need to be supported within the same framework to ensure good adherence and retention in care (Kranzer *et al*, 2010: 4).

The continuum of care provided by the different projects will be discussed in Chapter Five. The discussion will cover HCT, adherence preparation and support, OIs, ART, monitoring of patients, as well as the treatment outcomes of patients on ART.

The continuum of care starts with the patient entering care.

5.1. Entry into care

Entry into HIV care is dependent upon HIV diagnosis. Late entry into care is fundamentally linked to the risk of death (Grangeiro *et al*, 2011: 7). Health facilities providing care to patients with TB and STIs can offer a valuable opportunity for referral and linkage to HIV services, particularly for individuals who have less advanced HIV disease (Franke *et al*, 2011: 6; Keller, Jones and Erbelding, 2011: 237). Early access to HIV testing and care is therefore essential.

5.1.1. HIV Counseling and Testing

The detection of HIV-infection by standard serologic techniques may be difficult during the seroconversion period, while the diagnosis during the chronic disease is relatively easy. Most patients are asymptomatic for several months to several years following primary HIV-infection (Holodniy and Busch, 2003: 3). Tests for HIV diagnosis have historically used assays that detect antibodies against HIV-specific antigens (Holodniy and Busch, 2003: 4). The majority of the patients tested in the SACBC program are diagnosed by rapid HIV tests. These tests also use the test format referred to as the enzyme-linked immunosorbent assay (Foundation for Professional Development, 2010: 42).

Respondents were asked about the location of their first HIV-positive test Table 5.1 demonstrates that the majority of the respondents (94.29 - 97.21%) tested positive in the same province as the SACBC project they attended for ART. The respondents were not asked about the project/ facility at which they tested. The question was framed to establish the geographical area as the researcher wanted to establish if patients migrated into the area due to the availability of ART at the projects. This does not seem to be the case.

Only two (0.20%) of the respondents tested positive outside South Africa even though according to section 4.6.2 on migration, twenty-two (2.19%) respondents came from outside South Africa. The projects under review do not seem to have a large influx of foreigners seeking ART in South Africa. The data might be biased as patients might not have declared their foreign status due to fear of xenophobia.

Table 5.1 Location of first HIV-positive test

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Province	Gauteng	2.78% (n=9)	**94.29% (n=198)**	1.39% (n=4)	1.62% (n=3)	21.27% (n=214)
	KZN	**96.60% (n=313)**	0.95% (n=2)	0.35% (n=1)	0.00%(n=0)	**31.41% (n=316)**
	Limpopo	0.00% (n=0)	0.48% (n=1)	0.35% (n=1)	**96.76% (n=179)**	17.99% (n=181)
	North West	0.00% (n=0)	3.33% (n=7)	**97.21% (n=279)**	0.54%(n=1)	28.53% (n=287)
	Other	0.62% (n=2)	0.95% (n=2)	0.70% (n=2)	1.08% (n=2)	0.08% (n=8)
Country	ZAR	**100.00% (n=324)**	**100.00% (n=210)**	**99.65% (n=285)**	**99.46% (n=184)**	**99.80% (n=1003)**
	Other	0.00% (n=0)	0.00% (n=0)	0.35% (n=1)	0.54% (n=1)	0.20% (n=2)

* One respondent at Tapologo did not respond

The respondents were asked about the reason for having an HIV test at the time. Three-quarters of the respondents (75.75%, n=762) reported that they tested for HIV because they became ill, as tabulated in Table 5.2. Only the main categories were recorded, responses were not mutually exclusive.

Table 5.2 Reasons for having an HIV test

Reason	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Without knowledge	0.00% (n=0)	0.00% (n=0)	2.09% (n=6)	3.78% (n=7)	1.29% (n=13)
Became ill	**79.63% (n=258)**	**71.90% (n=151)**	**81.88% (n=235)**	**63.78% (n=118)**	**75.75% (n=762)**
Routine care	3.40% (n=11)	0.48% (n=1)	0.35% (n=1)	0.54% (n=1)	1.39% (n=14)
Partner infected	**5.25% (n=17)**	7.62% (n=16)	**4.88% (n=14)**	7.03% (n=13)	5.96% (n=60)
Child infected	2.47% (n=8)	0.95% (n=2)	0.35% (n=1)	3.24% (n=6)	1.69% (n=17)
Volunteer	1.85% (n=6)	**13.33% (n=28)**	2.79% (n=8)	**8.11% (n=15)**	5.67% (n=57)
Pregnant	**7.72% (n=25)**	**8.10% (n=17)**	**5.57% (n=16)**	**10.27% (n=19)**	7.65% (n=77)

The 77 females (7.65% of respondents) tested during pregnancy experienced HIV testing as part of routine antenatal care (ANC) in South Africa (South Africa, National Department of Health, 2010: 18). A small percentage of respondents tested because their partner was found to be infected (5.96%, n=60) and only 5.67%

(n=57) volunteered to be tested. This paints a gloomy picture for the drive for all in South Africa to know their HIV status, as the majority of individuals were only tested for HIV once they had a reason (became ill, became pregnant or a partner was found infected).

Once a patient is found to be HIV-infected the patient needs to be enrolled into HIV care. In the SACBC program a large part of the initial care is provided in the community. Community-based care will be discussed in great detail in Chapter Six.

In the continuum of care one of the first orders of business is to provide support to the newly identified HIV-infected person. As a measure of support and acceptance of their HIV status, the respondents were asked whether they had disclosed their HIV status to anyone. Disclosure is believed to positively affect health, mental health, disease transmission and the quality of relationships (Arnold *et al*, 2008: 91).

5.1.1.1. Disclosure

Patients who accept their seropositive status can face the challenges of treatment and this has a positive outcome on adherence (Vervoort *et al*, 2009: 433, 436). Most non-acceptors do not disclose their seropositive status. Attaining acceptance of the role of HIV in one's life is not only important to the quality of a patient's life, but also to the success of the treatment (Vervoort *et al*, 2009: 437).

Disclosure of one's seropositive status to significant others has its advantages and disadvantages (Peretti-Watel *et al*, 2006: 254). Disclosure can decrease the burden of secrecy, and open the possibility of emotional support, access to appropriate healthcare services and supportive resources, help partners share the responsibility for safe sexual practices, and lead to acceptance of the condition (Benotsch *et al*, 2008: 340; Peretti-Watel *et al*, 2006: 254; Skogmar *et al*, 2006: 279; Moneyham *et al*, 1996: 218). Patients who shared their seropositive status with family members seem to do better on treatment (CAFOD, 2008: 8). Some patients might, however, choose nondisclosure, especially when they are first diagnosed, primarily to protect themselves from rejection, stigma, harsh judgment, or difficult practical ramifications from their family, Church, or employer (Poindexter and Shippy, 2010: 37; Cusick, 1999: 14; Moneyham *et al*, 1996: 218). Moneyham *et al* (1996: 218) reported that the perception that a negative response might be forthcoming was sufficient reason not to disclose, even if access to needed resources and support was sacrificed. Table 5.3 tabulates the respondents' responses to questions related to disclosure.

Table 5.3 Disclosure of status

Indicator		**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Disclosed	Yes	**97.84% (n=317)**	**98.57% (n=207)**	**90.59% (n=260)**	**96.22% (n=178)**	**95.63% (n=962)**
	No	2.16% (n=7)	1.43% (n=3)	9.41% (n=27)	3.78%(n=7)	4.37% (n=44)
Disclosed to	Siblings	**52.05% (n=165)**	**74.40% (n=154)**	**77.69% (n=202)**	**82.02%(n=146)**	**69.33% (n=667)**
	Parent(s)	**55.52% (n=176)**	**62.80% (n=130)**	**55.38% (n=144)**	**66.29%(n=118)**	**59.04% (n=568)**
	Partner	**52.37% (n=166)**	**57.49% (n=119)**	**58.08% (n=151)**	**58.99%(n=105)**	**56.24% (n=541)**
	Child	**78.85% (n=41)**	**50.72% (n=105)**	46.54% (n=121)	**66.29% (n=118)**	**55.24% (n=385)**
	Other Relative	43.53% (n=138)	**63.29% (n=131)**	**51.92% (n=135)**	**68.54%(n=122)**	**54.68% (n=526)**
	Friends	35.96% (n=114)	**58.94% (n=122)**	**49.62% (n=129)**	**58.43%(n=104)**	48.75% (n=469)
	Community	24.92% (n=78)	47.34% (n=98)	31.15% (n=81)	46.07%(n=82)	35.34% (n=340)

In the study the vast majority (95.63%, n=962) of the respondents disclosed their HIV status to someone. More than half of the patients indicated they disclosed to their siblings (69.33%, n=667), parents (59.04%, n=568), partners (56.24%, n=541), children (56.24%, n=385) and other relatives (54.68%, n=526), while slightly fewer respondents (48.75%, n=469) disclosed to trusted friends and 35.34% (n=340) disclosed to the community. More respondents at St Apollinaris disclosed to their children than at the other projects.

The disclosure patterns of respondents in this study are slightly different from patterns found by others. Peretti-Watel *et al* (2006: 256) found that disclosure was most frequent to friends and siblings with high incidence of concealment from children and other relatives. There was a balance between disclosure and concealment with parents while concealment was uncommon with partners. Skogmar *et al* (2006: 728) also found high rates of disclosure (92%); however, the disclosure to partners was lower at 21%, suggesting that stigma exists in these intimate relationships. Arnold *et al* (2008: 86) concluded that family members are often the first to learn of an individual's status. One of the issues directly related to the importance of disclosure to families is caregiving. In many instances the family members care for those who become too ill to care for themselves.

All HIV-infected individuals will suffer from OIs when immunodeficiency appears (Webster, 1992: 288). Many of these opportunistic pathogens are ones that established latent or dormant infection earlier in life, with or without symptomatic disease, and re-emerge from latency with immunodeficiency. Screening for, preventing and treating OIs is an important part of the continuum of care.

5.2. Opportunistic infections

Immunosupression is associated with a variety of OIs. Some (like candidaisis) can occur at a CD4 count around 500 cells/mm^3, but the majority will appear with advanced HIV-infection, when the CD4 count is below 200 cells/mm^3 (Foundation for Professional Development, 2010: 93). The clinical manifestations associated with

HIV-infection vary in different populations according to the relative frequency of other endemic OIs (Quinn *et al*, 1986: 960). Maartens (2010: 480) lists TB, oesophageal candidiasis, bacterial pneumonia, chronic herpes simplex ulcers (an STI) and diarrhoea as the five most common OIs (in order of importance) in South Africa. In a Zambian study HIV-positive individuals list TB (46.8%), diarrhea (12.9%) and STDs (5.8%) as the main causes of illness (Guinnes *et al*, 2003: 356).

5.2.1. Patients' experience of OIs

Respondents were asked about the OIs they experienced before and after commencing ART. Their responses are reflected in Table 5.4 and Table 5.5. Their responses were similar to those described by Maartens (2010: 480), although the order of importance was different. The sequence of conditions varied from site to site, but in all the sites diarrhea was the most common.

Table 5.4 OIs experienced before commencing ART

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
1) Diarrhea	52.78% (n=171)	48.57% (n=102)	38.68% (n=111)	33.51% (n=62)	44.33% (n=446)
2) STIs	51.54% (n=167)	34.76% (n=73)	33.45% (n=96)	21.08% (n=39)	37.28% (n=375)
3) PTB	45.99% (n=149)	35.24% (n=74)	31.36% (n=90)	32.97% (n=61)	37.18% (n=374)
4) Oral Candida	34.57% (n=112)	44.76% (n=94)	38.33% (n=110)	29.73% (n=55)	36.88% (n=371)
5) Herpes Zoster	27.47% (n=89)	34.29% (n=72)	26.13% (n=75)	18.38% (n=34)	26.84% (n=270)
TB (not PTB)	1.85% (n=6)	2.38% (n=5)	13.24% (n=38)	20.00%(n=37)	8.55% (n=86)
Other	2.78% (n=9)	3.34% (n=7)	1.05% (n=3)	0.54% (n=1)	1.99% (n=20)
Ca	1.23% (n=4)	0.48% (n=1)	1.05% (n=3)	0.54% (n=1)	0.89% (n=9)

PTB = pulmonary TB, TB (not PTB) = TB other than pulmonary TB, CA = carcinoma

The responses were more similar for OIs experienced after commencing ART than for those experienced before commencing ART, although the prevalence was much lower. This is to be expected as ART dramatically reduces the incidence of all OIs (Foundation for Professional Development, 2010: 93).

Table 5.5 OIs experienced after commencing ART

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
1) Diarrhea	36.11% (n=117)	18.10% (n=38)	16.72% (n=48)	9.73% (n=18)	21.97% (n=221)
2) Oral Candida	11.11% (n=36)	17.14% (n=36)	13.24% (n=38)	8.11% (n=15)	12.43% (n=125)
3) PTB	16.36% (n=53)	11.43% (n=24)	6.97% (n=20)	4.86% (n=9)	10.54% (n=106)
4) STIs	15.12% (n=49)	8.57% (n=18)	10.80% (n=31)	3.78% (n=7)	10.44% (n=105)
5) Herpes Zoster	8.64% (n=28)	7.62% (n=16)	8.71% (n=25)	7.57% (n=14)	8.25% (n=83)
TB (not PTB)	1.54% (n=5)	0.48% (n=1)	3.83% (n=11)	8.11%(n=15)	3.18% (n=32)
Other	2.78% (n=9)	2.86% (n=6)	1.05% (n=3)	**1.08% (n=2)**	1.99% (n=20)
Ca	0.93% (n=3)	**0.95% (n=2)**	0.70% (n=2)	0.54% (n=1)	0.80% (n=8)

STI = sexually transmitted infections, PTB = pulmonary TB, TB (not PTB) = TB other than pulmonary TB, CA = carcinoma

Although the sequence changed after commencing ART, the top five OIs experience remained the same. These will now be discussed briefly. The top five OIs experienced were diarrhea, candidiasis, TB, STIs and Herpes Zoster (discussed in the sequence of Table 5.5.)

5.2.1.1. Diarrhea

Diarrhea is a common condition in HIV-patients (Abong'o and Momba, 2008: 424; Evian, 2006: 131). In Zaire 68% of HIV-infected patients complained of diarrhea, while in Uganda and Tanzania up to 80% of patients reported unexplained diarrhea (Quinn *et al*, 1986: 960). Although diarrhea was the most commonly reported OI in this study, much lower numbers of participants suffered from it than those in Zaire, Uganda and Tanzania.

An excessive loss of fluid and electrolytes in the stool with at least three loose stools a day is defined as diarrhea. Diarrhea can be acute or chronic. Acute diarrhea can last up to two weeks while chronic diarrhea will last for longer than two weeks (Calles and Chang-Pitter, 2007: 222). Chronic and persistent diarrhea is a World Health Organization stage III disease and may cause serious dehydration, electrolyte loss and even weight loss (Evian, 2006: 131 Spencer, 2005: 151, 246) and may have a significant negative impact on the patient's QOL (Wilson and Fairall, 2010: 521).

A number of organisms or conditions may cause diarrhea in HIV-infected individuals, for example bacterial infections (salmonella, shigella, campylobacter, *Clostridium difficile* and *Escherichia coli*), parasites (cryptosporadia, microsporadia, isospora, giardia and amoeba), invasive diseases affecting the bowel (*mycobacterium avium* complex, cytomegalovirus, lymphoma, Kaposi's sarcoma and colon cancer), toxins and drugs (including antibiotic treatment and ART), diet (uncooked or contaminated food or water) and other causes (alcohol abuse, idiopathic HIV enteropathy, enteric viral infections, etc.) (Swanson, 2010: 170; Spencer, 2005: 151). Treatment varies in line with the causative agent. The PALSA PLUS (2010/11: 37) clinical guidelines for the primary care management of adults recommend initial oral rehydration and dietary advice. If the diarrhea persists for more than three weeks Loperamide can be used. Symptoms that persist after four weeks are classified as stage III disease; Cotrimoxazole is prescribed and the patient is referred to a doctor.

The second most overall OI experienced was Candidiasis (see Table 5.5).

5.2.1.2. Candidiasis

Candida albicans is the most common of the candida species that cause disease (Swanson, 2010: 76). Infections with this yeast are the most common fungal infections seen in HIV-infected individuals (Foundation for Professional Development, 2010: 102). Oropharyngeal candidiasis (oral thrush) was one of the first identifiers of HIV and is extremely common (Fichtenbaum, 2003 : 531). In the absence of ART and anti-fungal treatment, 60-90% of HIV-infected individuals will have Candida infection of oral mucous membranes (Spencer, 2005: 57). Persistent oral thrush is consistent with a CD4 cell count of less than 200 cells/mm^3. Signs and symptoms may include persistent dryness in the mouth, loss of taste, burning pain or discomfort in the mouth (Spencer, 2005: 57; Fichtenbaum, 2003 : 531).

In advanced immunodeficiency, the *C. albicans* can spread into the esophagus and trachea (Evian, 2006: 135). Esophageal candidiasis is a World Health Organization stage IV disease and necessitates ART (Spencer, 2005: 246). It presents with dysphagia (difficulty in swallowing), odynophagia (painful swallowing) and retrosternal (under the sternum) pain (Vazquez, 2003: 977).

The diagnosis of Candidiasis is usually made by the characteristic clinical appearance; a membranous or pseudo-membranous form presents as a white, blotting-paper like membrane that when removed would reveal an area of punctate erythema and bleeding beneath the area (Spencer, 2005: 57). The most important method of prevention is reversal of the immunodeficiency associated with HIV by initiating ART (Fichtenbaum, 2003 : 539). Antifungal agents for initial treatment of *Candida* infections are: Nystatin, Gentian violet, Amphotericin B and Cotrimoxazole (Foundation for Professional Development, 2010: 102; Spencer, 2005: 57). The client with dysphagia needs fluconazole 200mg daily for 14 days and ART (PALSA PLUS, 2010/11: 9). TB was next on the list according to Table 5.5.

5.2.1.3. TB

TB is the most serious and most common (although not in this study) OI, and is the leading cause of death among HIV-infected individuals worldwide (Foundation for Professional Development, 2010: 95; South Africa, National Department of Health, 2010: 22; Wilson and Fairall, 2010: 516; Van Dyk, 2008: 62; Gordin, 2003: 459). Latent TB infection (LTBI) is caused by *Mycobacterium TB*, an acid-fast bacillus (Swanson, 2010: 73). It is estimated that 2 billion people in the world are infected with latent *Mycobacterium TB*. The rate to progression of active TB (LTBI develops in active disease) is 10% in HIV-uninfected populations. However, disease progression is up to 100-fold higher in infected individuals (Swanson, 2010: 73, 74; Hornick, 2008: 249).

South Africa has a prevalence rate of 782/100,000 (World Health Organization, 2010a: 72).

TB is frequently one of the first manifestations of HIV-infection (Gordin, 2003: 461). Furthermore, nearly three quarters (73%) of the patients with TB are HIV-positive, making TB clinics an important place to do HCT to serve as an entry point into care (see section 5.1) (Churchyard and Corbett, 2010: 458). The high co-infection rate also necessitates the screening of all HIV-infected individuals for TB symptoms (South Africa, National Department of Health, 2010: 22).

All the SACBC projects use a set of five basic screening questions based on World Health Organization (1999: 72) guidance and a pilot instrument developed by the local CDC-office. The five questions relate to the presence of a chronic cough lasting for more than 2 weeks (might indicate pulmonary TB), fever, night sweat, weight loss and/or the presence of abnormal swelling (might indicate extra pulmonary TB). If a patient has two or more of the symptoms mentioned above the patient is referred for further management.

Although present in various regions of the body, TB is mostly found in the lungs (pulmonary TB). Pulmonary TB (PTB) is usually diagnosed using an acid-fast bacilli sputum test Manifestations of TB are similar in individuals with early HIV-infection and HIV-negative individuals. Once severe immunodeficiency sets in, TB can present atypically and becomes more difficult to diagnose and manage (Churchyard and Corbett, 2010: 457). The majority (40-60%) of HIV-infected individuals have sputum-negative disease, complicating the diagnosis of TB in HIV-infected individuals and ultimately their access to TB treatment (Wilson and Fairall, 2010: 516). All HIV-infected individuals with TB are potentially eligible for ART, because they are in either World Health Organization clinical stage III (PTB) or stage IV (extra pulmonary TB). In this study 59.15% (n=595) of the respondents had ever accessed TB treatment, while only 6.69% (n=70) were on TB treatment concurrently with ART during the study, as demonstrated in Table 5.6. New TB cases are treated with Rifampicin, Isoniazid (INH), Pyrazinamide and Ethambutol (PALSA PLUS, 2010/11: 37).

Table 5.6 TB treatment

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Receiving	Yes	10.49% (n=34)	4.29% (n=9)	5.57% (n=16)	5.95% (n=11)	6.69% (n=70)
	No	**89.51% (n=290)**	**95.71% (n=201)**	**94.43% (n=271)**	**94.05%(n=174)**	**93.04% (n=936)**
Ever on	Yes	46.60% (n=151)	37.14% (n=78)	37.63% (n=108)	40.00% (n=74)	40.85% (n=411)
	No	**53.40% (n=173)**	**62.86% (n=132)**	**62.37% (n=179)**	**60.00%(n=111)**	**59.15% (n=595)**

HIV-infection increases an individual's risk of recurrent TB disease, especially if the initial treatment regimen consisted of less than six months of Rifampicin, if there is post-TB scarring or cavities, or if the patient has a low CD4 count (Churchyard and Corbett, 2010: 460). The new ART guidelines (released in 2010) state that all TB patients with a CD4 count below 350 cells/mm^3 should receive ART (South Africa, National Department of Health, 2010: 6). Effective treatment for both TB and HIV is available and the two infections can be treated concurrently although it can pose some challenges (Kgwange and Budambula, 2010: 21). When treating HIV-infected individuals with active TB, it is important to provide optimal treatment for both infections. HIV-infected individuals will react well to standard anti-TB medication, although drug interactions are possible (Gordin, 2003: 465, 466). Furthermore, treating advanced HIV disease (AIDS) can lead to immune reconstitution inflammatory syndrome (where the immune system recovers, and then react unexpectedly to previously exposed infections) that is another potentially deadly complication (Churchyard and Corbett, 2010: 457). The occurrence of TB also affects the clinical course of HIV-infection by dramatically increasing HIV Ribonucleic acid (RNA) levels and a subsequent fast progression of HIV disease (Gordin, 2003: 460). TB treatment failure is not an option because it can lead to resistance and ultimately to extensive drug-resistant TB, a deadly form of the disease (98% mortality rate) (Wood and Martin, 2008: 281). HIV has thus turned TB into an increasingly complex epidemic putting everyone at risk (Kgwange and Budambula, 2010: 21).

Due to the importance of the co-infection, specific attention was paid to the respondents' TB history during the file audits. From the file audits it was shown that 34.83% (n=349) respondents had TB prior to commencing ART. As HIV-infected adults (with advanced disease) have an extremely high risk of reactivation of TB these 349 patients are at an increased risk for active TB either through reactivation of latent infection or from rapid progression to TB disease (Churchyard and Corbett, 2010: 458; Semba, Darnton-Hill and De Pee, 2010: 351). A further 6.39% (n=64) respondents developed TB after commencing ART. Seventy-eight (7.76%) were on TB treatment at the time. This is eight more than reported by the respondents (see Table 5.7). The majority (91.03%) of these respondents with recorded history of current TB treatment were on TB treatment for less than 6 months. These discrepancies might be due to respondents not disclosing that they were on TB treatment to the ART project staff or respondents not disclosing that they were on TB treatment to the fieldworkers. These findings are not unusual as individuals with advanced HIV-infection in South Africa generally have a high burden of TB disease. Lawn, Badri and Wood (2005: 2111) reported that 51% of patients initiated on ART in Cape Town had symptomatic disease and 14% had a previous episode of TB disease. File audit data related to TB are presented in Table 5.7.

Table 5.7 History of TB

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
TB before ART	Yes	**38.58% (n=125)**	**35.92% (n=74)**	**29.62% (n=85)**	**35.14% (n=65)**	**34.83% (n=349)**
	No	57.72% (n=187)	64.08% (n=132)	69.69% (n=200)	64.86%(n=120)	64.86% (n=639)
	No data	3.70% (n=12)	0.00% (n=0)	0.70% (n=2)	0.00%(n=0)	1.40% (n=14)
TB after ARV start	Yes	**8.33% (n=27)**	**3.86% (n=8)**	**3.85% (n=11)**	**9.73% (n=18)**	**6.39% (n=64)**
	No	89.81% (n=291)	95.65% (n=198)	95.80% (n=274)	90.27%(n=167)	92.81% (n=930)
	No data	1.85% (n=6)	0.48% (n=1)	0.35% (n=1)	0.00%(n=0)	0.80% (n=8)
Currently on TB Rx	**Yes**	**13.27% (n=43)**	**5.74% (n=12)**	**4.88% (n=14)**	**4.86% (n=9)**	**7.76% (n=78)**
	No	84.88% (n=275)	94.26% (n=197)	95.12% (n=273)	95.14%(n=176)	91.64% (n=921)
	No data	1.85% (n=6)	0.00% (n=0)	0.00% (n=0)	0.00%(n=0)	0.60% (n=6)
Duration on TB Rx	**0-6 months**	**100.0% (n=43)**	**91.67% (n=11)**	**57.14% (n=8)**	**4.86% (n=9)**	**91.03% (n=71)**
	6-12 months	0.00% (n=0)	8.33% (n=1)	35.71% (n=5)	0.00% (n=0)	7.69% (n=6)
	12-24 months	0.00% (n=0)	0.00% (n=0)	7.14% (n=1)	0.00% (n=0)	1.28% (n=1)

Rx= treatment

Fourth on the list of OIs experienced by the respondents were STIs.

5.2.1.4. Sexually transmitted infections

South Africa has one of the highest prevalence rates of STIs in the world (Hook and Schwebke, 2003: 674). In the Hlabisa district of KZN the Medical Research Counsel has shown that about 10% of young adults have at least one STI annually and that repeat episodes are frequent (Wilkinson *et al*, 2008: online). STIs are infections transmitted primarily through sexual intercourse (Van Dyk, 2008: 62,63,496).

There is a very close relationship and association between common STIs and HIV and they interrelate in different ways. STIs cause genital inflammation and damage to the surface of the natural barriers of the genital tract and therefore increase the risk of HIV transmission; they enhance the rate of progression of disease, while HIV alters the natural history of other STIs (Coetzee and Johnson, 2010: 216, 217; Friedel and Lavoie, 2008: 161; Evian, 2006: 261, 262). The care and prevention of STIs is therefore an important strategy in the prevention of HIV (Swanson, 2010: 35; Evian, 2006: 261). Health facilities that provide care to patients who present with STIs can play an important role in HCT and serve as an entry point into HIV care (see section 5.1) (Hook and Schwebke, 2003: 674). Individuals with known HIV-infection presenting with STIs need counseling and treatment as they put others at risk of contracting or being re-infected with HIV (Spencer, 2005: 168; Hook and Schwebke, 2003: 674).

Evian (2006: 264-266) states that STIs are infections caused by different bacteria, fungi, protozoa and viruses. Gonorrhea is caused by *gonococcus bacteria*, syphilis by *Treponema pallidum*, urethritis by *clamidia* and chancroid by *Haemophilus ducreyi*. These infections are all transmitted by sexual contact. Although the infections can be caused by a number of organisms they generally present with only a few symptoms, a discharge from the genital tract or a sore/ulcer on the genitals. Sometimes these symptoms will be accompanied by lower abdominal pain, burning on micturition/or swelling of lymph nodes. These general symptoms, the lack of diagnostics and the possibility of co-infection make a syndromic approach to treatment necessary. The basic treatment is Cefixime and Doxycycline with Metronidazole, while genital ulcers are treated with Benzathine penicillin, Erythromycin and Aciclovir (PALSA PLUS, 2010/11: 14-16).

Herpes Zoster (Shingles), caused by the varicella-zoster virus (VZV) is the last OI on the list to be discussed.

5.2.1.5. Herpes Zoster

Herpes Zoster is a member of the herpes family and humans are the only reservoir for VZV (Swanson, 2010: 63). Primary infection with VZV causes varicella (chickenpox). Virus latency is then caused in the host by the VZV. Reactivation of the VZV can lead to Herpes Zoster (Shingles) (Foundation for Professional Development, 2010: 110). The disease is prevalent among HIV-infected individuals due to their immunosuppression. Among Botswana HIV-infected patients 13% were clinically diagnosed with Herpes Zoster and in Zimbabwe 24% (Holmes *et al*, 2003: 659).

Symptoms are severe lancinating pains associated with cutaneous dysesthesias (abnormal sensation) and sometimes itch. Onset of the pain precedes the appearance of the lesions by 48-72 hours; the rash forms lesions over 3-5 days (following the distribution of the nerve root thus not crossing the midline) and resolves in 10-15 days. The unilateral rash appears as vesicles upon a background of dark or red skin and follows the underlying route of cranial or spinal nerves inflamed by VZV (Mosby, 1998: 757). General symptoms of fatigue, headache and malaise are common (Swanson, 2010: 63; Spencer, 2005: 39). The rash can be disseminated with bilateral skin involvement, but it is rare (Foundation for Professional Development, 2010; 110; Swanson, 2010: 63). An unusual sign that needs caution is vesicles on the nose (implying involvement of the cornea and potentially sight-threatening) (Foundation for Professional Development, 2010; Spencer, 2005: 39).

High doses of antivirals are indicated. Acyclovir, valaciclovir and famciclovir are indicated in uncomplicated VZV. Disseminated VZV infection necessitates intravenous acyclovir (Foundation for Professional Development, 2010: 110). Prevention is always better (and often easier) than cure. Several OIs can be prevented by prophylaxis.

5.2.2. Prophylaxis

Primary prophylaxis (preventing the infection before it occurs) is widely used (Foundation for Professional Development, 2010: 93) to minimize deaths associated with opportunistic diseases when immunodeficiency sets in. Although many drugs exist to treat OIs, the management of these infections in HIV-infected individuals can be complex. Preventing the OIs is therefore preferable. Many different options of prophylaxis are available, but many can be unaffordable and/or might not be applicable in an African setting (Foundation for Professional Development, 2010: 93; Evian, 2006: 112). Maartens (2010: 479) is of the opinion that the best way to prevent OIs is to restore immunity with ART, as it can reduce the occurrence of OIs by up to 80%. Some patients might, however, still need further prophylaxis. In South Africa the most common primary prophylaxis given is Cotrimoxazole and INH. At the time of the study some controversy surrounded the use of INH as TB preventative therapy in combination with ART (Churchyard and Corbett, 2010: 472). The study therefore focused on the use of Cotrimoxazole.

5.2.2.1. Cotrimoxazole

Cotrimoxazole is a combination of Trimethoprim and Sulfamethoxazole (Grahame-Smith and Aronson, 1984: 669). These two compounds are used in combination to treat bacterial infections, especially *Pneumocystis jiroveci*, toxoplasmosis, isoporiasis, bacteraemia and bacterial pneumonia (Foundation for Professional Development, 2010: 93; Maartens, 2010: 480). It is more effective than any other preventative therapy and should be used whenever possible (Mayer and Cohen, 2003: 715). All HIV-infected individuals who are either clinically (World Health Organization stage 3 or 4) or immunologically (CD4 count less than 350) immune suppressed should receive Cotrimoxazole (Foundation for Professional Development, 2010: 93). The drug is well tolerated and 60-80% of individuals will not have any adverse reactions to it (Foundation for Professional Development, 2010: 93; Maartens, 2010: 485). Large numbers of respondents (81.81%, n=823) indicated they had been on Cotrimoxazole while nearly three quarters (74.24%, n=611) were still on it, as indicated in Table 5.8.

Table 5.8 Cotrimoxazole

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Ever on	Yes	**67.59% (n=219)**	**96.67% (n=203)**	**85.71% (n=246)**	**83.78% (n=155)**	**81.81% (n=823)**
	No	32.41% (n=105)	3.33% (n=7)	14.29% (n=41)	16.22%(n=30)	18.19% (n=183)
Still on	Yes	**74.43% (n=163)**	**80.79% (n=164)**	**95.12% (n=234)**	**32.26% (n=50)**	**74.24% (n=611)**
	No	25.57% (n=56)	19.21% (n=39)	4.88% (n=12)	67.74%(n=105)	25.76% (n=212)

Other African countries have used Cotrimoxazole effectively. For example, a 46% reduction in mortality, and reductions in diarrhea, clinic visits and hospital admissions were ascribed to the use of Cotrimoxazole in rural Uganda (Mermin *et al*, 2004: 1432). Cotrimoxazole prophylaxis is particularly useful for people with a CD4 count too high for ART to be appropriate and daily use also lays the groundwork for medication adherence by patients (Mermin *et al*, 2004: 1428).

5.3. Adherence preparation

ART cannot be effective if patients do not adhere to the regimen as current treatment is capable of reversing, but not curing, HIV-associated immunodeficiency. Suboptimal adherence has been associated with less durable viral suppression (Mayer and Cohen, 2003: 715). Interventions targeting practical medication management skills for individuals or groups could improve adherence to ART (Rueda *et al*, 2009: 8, 9). Three interventions towards adherence support provided will be discussed, namely adherence training, the use of treatment buddies, and support groups.

5.3.1. Adherence training

Adherence training was provided in group sessions (with individual attention during consultations) at all the projects. Eligible prospective ART patients and their chosen treatment buddies attended an average of three adherence training sessions. Table 5.9 shows that 90.76% (n=913) of the respondents attended adherence training. The staff members who provided the training varied. At St Apollinaris (88.10%, n=237) and Bela-Bela (89.16%, n=148) the majority of respondents were trained by counselors, indicating nearly complete task-shifting of adherence training away from registered nurses. Task-shifting will be discussed further in Chapter Six. Hope for Life respondents reflected that the main trainers were registered nurses (61.27%, n=125) with some assistance from counselors (28.92%, n=59), indicating partial task-shifting. Adherence training duties at Tapologo were nearly evenly managed by counselors (49.08%, n=134) and registered nurses (46.52%, n=127). Overall respondents viewed the training as effective (98.68%, n=900) and felt well prepared (94.52%, n=862) regardless of the cadre that provided the training. Attendance at St Apollinaris was slightly lower than at the other projects, thus the slightly lower feeling of preparedness.

Table 5.9 Adherence training

Indicator		**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Attended	Yes	**83.02% (n=269)**	**97.72% (n=205)**	**95.12% (n=273)**	**89.73% (n=166)**	**90.76% (n=913)**
	No	16.98% (n=55)	1.90% (n=4)	4.88% (n=14)	10.27%(n=19)	9.15% (n=92)
Main trainer	Counselor	**88.10% (n=237)**	**28.92% (n=59)**	**49.08% (n=134)**	**89.16% (n=148)**	63.38% (n=578)
	Registered nurse	10.41% (n=28)	**61.27% (n=125)**	**46.52% (n=127)**	10.24% (n=17)	32.57% (n=297)
	Doctor	1.12% (n=3)	9.31% (n=19)	1.83% (n=5)	0.60% (n=1)	3.07% (n=28)
	Other	0.37% (n=1)	0.49% (n=1)	2.56% (n=7)	0.00% (n=0)	0.99% (n=9)
Effectiveness	Not at all	0.74% (n=2)	0.49% (n=1)	0.37% (n=1)	1.20% (n=2)	0.66% (n=6)
	A little	1.49% (n=4)	0.00% (n=0)	0.73% (n=2)	0.00% (n=0)	0.66% (n=6)
	Very	**97.77% (n=263)**	**99.51% (n=203)**	**98.90% (n=270)**	**98.80% (n=164)**	**98.68% (n=900)**
Felt prepared	Yes	**89.59% (n=241)**	**96.08% (n=196)**	**96.34% (n=263)**	**97.59% (n=162)**	**94.52% (n=862)**
	Mostly	7.43% (n=20)	3.92% (n=8)	2.93% (n=8)	1.81% (n=3)	4.28% (n=39)
	No	2.97% (n=8)	0.00% (n=0)	0.73% (n=2)	0.60% (n=1)	1.21% (n=11)

Participants were asked about the topics they were trained on. Their responses are tabulated in Table 5.10. Reported topics were grouped together, hence the number of responses could outnumber the number of participants. The trainings mainly included information on ART (111.1%, n=1014) and instructions on how to live with HIV (Wellness, 88.39%, n=807). Responses were not mutually exclusive.

Table 5.10 Topics trained on

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
ART info	**107.4%(n=289)**	**100.5%(n=206)**	107.7%(n=294)	**135.5%(n=225)**	111.1%(n=1014)
Wellness	68.40%(n=184)	44.88%(n=92)	**123.4%(n=337)**	116.9%(n=194)	88.39%(n=807)
HIV prevention	42.01%(n=113)	37.08%(n=76)	44.3%(n=121)	53.61%(n=89)	43.70%(n=399)
Importance of adherence	17.84%(n=48)	17.08%(n=35)	25.64%(n=70)	24.70%(n=41)	21.25%(n=194)
Side-effects	8.92%(n=24)	8.29%(n=17)	7.69%(n=21)	14.46%(n=24)	9.42%(n=86)
General HIV info	9.29%(n=25)	7.80%(n=16)	6.59%(n=18)	1.81%(n=3)	6.79%(n=62)
Need for support	5.95%(n=16)	12.68%(n=26)	4.40%(n=12)	3.61%(n=6)	6.57%(n=60)
Follow-up visits	4.09%(n=11)	1.95%(n=4)	1.10%(n=3)	1.20%(n=2)	2.19%(n=20)
No response	0.74%(n=2)	0.00%(n=0)	0.00%(n=0)	0.00%(n=0)	0.22%(n=2)

Treatment buddies were also used as adherence support intervention at all the projects.

5.3.2. Treatment buddies

Patients eligible for ART in the SACBC program were asked to nominate a treatment buddy, who is someone to whom the patient has disclosed. The treatment buddy attended adherence training with the patient and served as an alternative contact person for the project if the patient could not be reached. This person provided peer education and support for the patient (Van Wyk, 2005: 83).

Table 5.11 summarizes the utilization of treatment buddies. Nearly three quarters (74.88%, n=751) of the respondents reported that they had a treatment buddy. Of these respondents the majority (96.53%, n=723) found the treatment buddies effective adherence supporters.

Table 5.11 Treatment buddies

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Identified	Yes	**77.78% (n=252)**	**76.19% (n=160)**	**66.20% (n=188)**	**81.62% (n=151)**	**74.88% (n=751)**
	No	22.22% (n=72)	23.81% (n=50)	33.80% (n=96)	18.38%(n=34)	25.12% (n=252)
Effectiveness	Not at all	0.40% (n=1)	0.63% (n=1)	0.00% (n=0)	0.00% (n=0)	0.27% (n=2)
	A little	5.58% (n=14)	2.50% (n=4)	2.14% (n=4)	1.32% (n=2)	3.20% (n=24)
	Very	**94.02% (n=236)**	**96.88% (n=155)**	**97.86% (n=183)**	**98.68% (n=149)**	**96.53% (n=723)**

Bekker *et al* (2003: 462) further advise that HIV-infected individuals should be used as treatment buddies and counselors as these individuals can be an untapped resource of expertise and talent. Another form of support available to the patients on ART in the SACBC projects was support groups.

5.3.3. Support groups

Support groups have been used widely in other conditions, since 1906. Given the nature and dimensions of traumatic stress, it is reasonable to suggest a diagnosis of AIDS constitutes a traumatic event necessitating additional psychological support (Gabriel, 1996: 6). Support groups can provide the psychological support needed by HIV-infected individuals as existing health institutions' networks can often not meet all the HIV-infected individual's psychological needs. The unmet needs can often be alleviated by mutual aid provided by people who share a common experience (Mahilal, 2006: 77). The essential elements of a support group include instillation of hope, imparting information, altruism, group cohesiveness, catharsis and existential reconnection (Gabriel, 1996: 14).

Support groups were not well utilized at St Apollinaris as tabulated in Table 5.12. Only 17.59% (n=57) of the St Apollinaris respondents attended support groups. The utilization of support groups at the other projects was more balanced with 63.78% (n=118) of respondents at Bela-Bela utilizing a support group, 63.76% (n=183) of the respondents at Tapologo and 53.33% (n=112) of the respondents at Hope for Life.

Table 5.12 Support groups

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Attend	Yes	17.59% (n=57)	**53.33% (n=112)**	**63.76% (n=183)**	**63.78% (n=118)**	46.72% (n=470)
	No	**82.41% (n=267)**	46.67% (n=98)	36.24% (n=104)	36.22%(n=67)	**53.28% (n=536)**
Location	At facility	**31.58% (n=18)**	**64.29% (n=72)**	**97.27% (n=178)**	**94.92%(n=112)**	80.85% (n=380)
	Community	**64.91% (n=37)**	**34.82% (n=39)**	2.19% (n=4)	5.08%(n=6)	18.30% (n=86)
	Other	3.51% (n=2)	0.89% (n=1)	0.55% (n=1)	0.00%(n=0)	0.85% (n=4)
Effectiveness	Not at all	1.75% (n=1)	0.91% (n=1)	1.10% (n=2)	0.00%(n=0)	0.86% (n=4)
	A little	8.77% (n=5)	1.82% (n=2)	1.10% (n=2)	0.00%(n=0)	1.93% (n=9)
	A lot	89.47% (n=51)	97.27% (n=107)	97.80% (n=178)	100.0%(n=118)	97.22% (n=454)

The location of the support groups varied. Support groups were held mainly at facilities at Tapologo (94.27%, n=178) and Bela-Bela (94.92%, n=112) while the other two projects had a mix between facility and community-based support groups. At St Apollinaris the majority (64.91%, n=37) of the respondents attended a support group in the community, while only 18 (31.58%) of the respondents attended a facility-based support group. The situation was reversed at Hope for Life with the majority at the facility (64.29%, n=72) and nearly a third (34.82%, n=39) in the community.

Once the patients have completed adherence training and have identified support structures, ART is initiated for those eligible for treatment.

5.4. Antiretroviral treatment

The primary aim of ART is to achieve HIV viral suppression and reduce the level of HIV RNA as much as possible, for as long as possible to stop or delay the inevitable progression to AIDS and the subsequent death of HIV-infected individuals (Wilson and Fairall, 2010: 531; Evian, 2006: 79). However, successful therapy will not always prevent further clinical events. Ten to fifteen percent of patients with advanced disease (CD4 <50 cells/mL) initiated on ART can still have an AIDS-defining diagnosis (Wilson and Fairall, 2010: 531). Although ART can delay the progression of HIV disease, it is not a cure.

5.4.1. ART is not a cure for HIV

Most ART agents target the reverse transcriptase step in the life cycle of HIV. Nucleoside agents (Zidovudine and Lamivudine) act by becoming incorporated in the growing Deoxyribonucleic acid (DNA) chain and interfering with continued transcription of the genomic RNA of the virus. Nonnucleoside agents (Nevirapine and Efavirenz) target their reverse transcriptase enzyme itself by binding to a unique project within the enzyme that alters its ability to function (Mayers, 2003: 145). Successful ART can thus cripple the virus, but cannot eradicate it. The HI-Virus is a retrovirus, which is an enveloped RNA virus that has the capacity to make a DNA copy of itself through its characteristic enzyme, reverse transcriptase. This enzyme reverses the normal process of gene replication and enables the virus to establish latency, making HIV a lifelong infection (Webster, 1992: 289).

Paredes, Sherer and Clotet (2008: 422) and Wilson and Fairall (2010: 531) summarize why ART is unable to clear HIV. Eradication is prevented as the HIV:

- ✓ infects the human CD4 lymphocytes and macrophages and undermines the body’s own immune system by using it to replicate HIV and decrease immune response.
- ✓ permanently incorporates its DNA into the human genome.
- ✓ mutates rapidly and adapts to different environments.
- ✓ infects latent cellular viral reservoirs in different areas of the body.
- ✓ alters its surface proteins in order to evade the human immune response by masking the body’s own glycoproteins.

Although triple therapy ART should provide viral suppression, restore immune function and improve QOL, not all HIV-infected individuals are eligible for ART (Spencer, 2005: 4).

5.4.2. Criteria for receiving ART

In South Africa the public roll-out was designed as a structured program utilizing standardized treatment guidelines (Gounden, 2011: 8). From 2004 up to 2010 the following criteria were used to determine eligibility for ART in adults and adolescents.

- ✓ CD4 count less than 200 cells/mm^3 irrespective of World Health Organization stage, or
- ✓ World Health Organization stage 4 disease (see Table 5.13) irrespective of CD4 count, and
- ✓ Patients express willingness and readiness to take ART adherently (South Africa, National Department of Health, 2004: 3).

Table 5.13 World Health Organization stage 4 (AIDS-defining conditions)

HIV wasting syndrome
Pneumocystis jiroveci pneumonia
Toxoplasmosis of an internal organ
Cryptosporidiosis with diarrhea, more than 1 month
Cryptosporidiosis, extrapulmonary
Cytomegalovirus (disease of an organ other than the liver, spleen or lymph nodes)
Herpes simplex virus infection, Mucocutaneous more than 1 month, or visceral (any duration)
Progressive multifocal leuko-encephalopathy
Any disseminated endemic mycosis (i.e. histoplasmosis, coccidioidomycosis)
Candidiasis of the esophagus, trachea, bronchi or lungs
Atypical mycobacteriosis, disseminated
Non-typhoid salmonella septicemia
Extrapulmonary TB
Lymphoma
Kaposi's sarcoma
HIV encephalopathy or dementia

Source: (Evian, 2006: 118)

Two ART regimens were recommended for use in the South African public sector between 2004 and 2010. The recommended ART regimens were:

1A) d4T/3TC/EFV, or

1B) d4T/3TC/NVP, and as second-line

2) AZT/ddI/LPV/r (South Africa, National Department of Health, 2004: 4)

These drugs are discussed further in section 5.4.5. The ART guidelines further distinguish between ART naïve (no previous exposure to ART) patients and previously exposed patients. Naïve patients were to start on one of the first-line regimens (1a or 1B) and for previously exposed patients guidance from an ART expert was indicated before treatment could commence (South Africa, National Department of Health, 2004: 5).

5.4.3. Treatment naïve patients

The majority (86.26%, n=854) of the respondents' files indicated that they were treatment naïve as tabulated in Table 5.14. A small group (4.65%, n=46) was recorded as having been transferred into the projects, with no treatment disruptions, while treatment disruptions had occur in only 0.61% (n=6) of respondents, decreasing the expected prevalence of resistance. A sizable portion (8.48%, n=84) had no data recorded.

Table 5.14 History of ART

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Previous ART	Yes (no disruption)	6.71% (n=21)	1.46% (n=3)	4.18% (n=12)	5.41% (n=10)	4.65% (n=46)
	Yes (disruption)	1.28% (n=4)	0.00% (n=0)	0.70% (n=2)	0.00% (n=0)	0.61% (n=6)
	ART naïve	70.61% (n=221)	91.22% (n=187)	94.43% (n=271)	94.59% (n=175)	86.26% (n=854)
	No data	21.41% (n=67)	7.32% (n=15)	0.70% (n=2)	0.00% (n=0)	8.48% (n=84)

The respondents' files showed that 52 (5.26%) respondents had previous ART exposure (as indicated in Table 5.14), while only 45 (4.47%) respondents reported during the interviews that they had had previous exposure. Data quality was lower at St Apollinaris. The results from the structured interviews are reflected in Table 5.15. The small group of respondents who had previous exposure were not on treatment for long at the previous project (median 0.67 years).

Table 5.15 Patients previously exposed to ART

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
ART naive	Yes	**95.06% (n=308)**	**98.57% (n=207)**	**94.08% (n=270)**	**95.14% (n=176)**	**95.53% (n=961)**
	No	4.94% (n=16)	1.43% (n=3)	5.92% (n=17)	4.86%(n=9)	4.47% (n=45)
Duration of exposure (years)	Minimum	0.00	0.16	0.08	0.17	0.00
	Median	0.54	0.67	1.00	0.67	0.67
	Maximum	6.25	2.00	5.00	4.42	6.25
Treatment disruption	Yes	**25.00% (n=4)**	**0.00% (n=0)**	**23.53% (n=4)**	**0.00% (n=0)**	**16.95% (n=8)**
	No	75.00% (n=12)	100.00% (n=3)	76.47% (n=13)	100.00% (n=6)	83.05% (n=34)

The majority of the respondents was therefore treatment naïve and could be initiated on a first-line regimen.

5.4.4. Initiation

As prescribed by the National ART guidelines (South Africa, National Department of Health, 2004) the first-line regimens consist of a non-nucleoside reverse transcriptase inhibitor (NNRTI) (Efavirenz or Nevirapine) together with the nucleoside reverse transcriptase inhibitors (NRTIs) (Stavudine and Lamivudine). Nevirapine is the preferred NNRTI for women of child-bearing age and Efavirenz the lead choice when combined with a Rifampicin-containing TB treatment regimen (Wood and Martin, 2008: 279). The second-line regimen consists of Zidovudine, Didanosine and Protease Inhibitors (PI) Ritonavir boosted Lopinavir (Wood and Martin, 2008: 279).

As indicated in Table 5.16 first-line regimens were used to initiate the respondents on treatment. The majority of respondents started on d4T (98.92%, n=989) and 3TC (98.51%, n=991) and EFV (83.00%, n=835) or NVP (16.50%, n=166). The anomaly here is that with a predominantly female (70.58%, see section1) group of childbearing age (median 37.49 years) one would expect more respondents on NVP. The researcher has to ascribe this to the staff using their own professional judgment. Very few (less than 1.00%) respondents were started on second-line regimens testifying once again to the naïve nature of the ART respondents.

Table 5.16 ART regimen started on

ART	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
d4T	**99.07% (n=321)**	**99.05% (n=208)**	**96.52% (n=277)**	**96.52% (n=183)**	**98.92% (n=989)**
3TC	**99.38% (n=322)**	**99.05% (n=208)**	**97.21% (n=279)**	**98.38% (n=182)**	**98.51% (n=991)**
EFV	**87.04% (n=282)**	**71.43% (n=150)**	**98.95% (n=284)**	**64.32% (n=119)**	**83.00% (n=835)**
NVP	**12.96% (n=42)**	**28.10% (n=59)**	0.35% (n=1)	**34.59% (n=64)**	**16.50% (n=166)**
ZDV	0.62% (n=2)	0.00% (n=0)	0.35% (n=1)	1.08% (n=2)	0.50% (n=5)
DDI	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.54% (n=1)	0.10% (n=1)
LPV/r	0.62% (n=2)	0.48% (n=1)	0.00% (n=0)	1.62% (n=3)	0.60% (n=6)
Combivir	0.00% (n=0)	0.95% (n=2)	2.79% (n=8)	0.00% (n=0)	0.99% (n=10)

The antiretroviral agents the respondents were started on will now be discussed.

5.4.5. Types of Antiretroviral agents

Antiretroviral agents belong to different pharmacological classes (Spencer, 2005: 14). In the SACBC program three classes of ART were used. They are the:

- ✓ Nucleoside reverse transcriptase inhibitors (NRTIs), and
- ✓ Non-nucleoside reverse transcriptase inhibitors (NNRTIs), and
- ✓ Protease inhibitors (PIs).

These classes and the antiretroviral agents used from them will now be discussed briefly and summarized in Table 5.17.

Table 5.17 Antiretroviral agents

Generic name	**Abbreviation**	**Trade name**	**Dose**	**Side-effects**
Nucleoside reverse transcriptase inhibitors (NRTIs)				
Didanosine	DDI	Videx,	125mg bd <60kg 200mg bd> 60kg	Peripheral neuropathy, pancreatitis, nausea, diarrhea
Lamivudine	3TC	Epivir	150mg bd	Anaemia, GI upset, myalgia (rare), neutropenia, headaches
Stavudine	d4T	Zerit	30mg bd	Headaches, chills, fever, diarrhea, rash, nausea, vomiting, abdominal pain, myalgia, insomnia, pancreatitis, **neuropathy**, hyperamylasemia, elevated AST, elevated ALT, anemia and neutropenia
Zidovudine	AZT, ZDV	Retrovir	300mg bd	Bone marrow suppression **(anemia),** GI upset, headache, myopathy, fatigue, myalgia, insomnia, anorexia, neutropenia, nail pigmentation, fever, rash, hepatitis and hyperlactatemia
Non-nucleoside reverse transcriptase inhibitor (NNRTI)				
Efavirenz	EFV	Stocrin	600mg qid	CNS symptoms (53% pt.), fatigue, pain, dizziness, headache, concentration impaired, inscemnia, abnormal dreams, somnolence, anorexia, nausea, vomiting, diarrhea, dyspepsia, abdominal pain, anxiety, depression, nervousness, rash, pruritus and increased sweating, teratogenicity potential, elevated transaminases
Nevirapine	NVP	Viramune	200mg daily (2/52), 200mg bd	**Rash**, elevated transaminases, fever, fatigue, headaches, somnolence, nausea, **hepatic toxicity**, liver enzyme elevations and chemical hepatitis.
Protease inhibitors (PIs)				
Lopinavir	Only used in combination			
Ritonavir	RTV	Norvir	600mg bd	GI upset , circumoral and extremities paresthesias, diarrhea, fatigue, hepatitis, taste perversion, hyperglycemia
Fix dose combinations				
Lopinavir, boosted with Ritonavir	LPV/r	Aluvia, Kaletra	400mg Lopinavir & 100mg Ritonavir bd	These PIs share common side-effects as listed above
Zidovudine & Lamivudine	ZDV & 3TC	Combivir	300mg Zidovudine & 150 mg Lamivudine bd	See individual agents

Source: (Wilson and Fairall, 2010: 534-536; Eron, 2003: 86; Fischl, 2003: 24; Mayers, 2003: 147; Montaner and Lange, 2003: 135; Pavia, 2003: 68), GI = Gastrointestinal, AST = aspartate aminotransferase, ALT = alanine transaminase (ALT and AST is blood tests to determine liver function) ,CNS = central nervous system.

As indicated in Table 5.17 these antiretroviral agents have several side-effects, some of them life-threatening.

5.4.6. Side-effects

In resource-poor settings drug choices are cost-driven. Therefore drugs that were developed earlier and generic drugs are used due to their lower cost These drugs have more side-effects than the newer more expensive drugs (Beck and Walensky, 2008: 55). Drugs used in the first-line regimen in South Africa can cause serious metabolic complications. Calls have been made to substitute Stavudine (d4T) in the first-line regimen with a nucleotide reverse transcriptase inhibitor (NtRTI) Tenofovir (Wood and Martin, 2008: 282). Subsequently Tenofovir was included in the ART guidelines published in 2010 (South Africa, National Department of Health, 2010). Though all the antiretroviral agents have side-effects, not all the side-effects occur at the same duration of treatment and all are not life-threatening. Short-term toxicity occurs within the first few weeks of therapy, of which, for example, Steven-Johnson's syndrome (a life-threatening skin condition) may be fatal. Nevertheless most of the early onset toxicities will clear up and seldom necessitate the disruption of treatment (Paredes, Sherer and Clotet, 2008: 428, Barlett and Gallant, 2003: 338). Long-term toxicities have a sub-acute or chronic onset and can go unnoticed for years. They may have a profound impact on the patient's physical, psychological and social life and may compromise adherence (Paredes, Sherer and Clotet, 2008: 429).

Respondents were asked about the side-effects they had experienced. Their responses are shown in Table 5.18. Nearly two-thirds (61.13%, n=615) of the respondents experienced some side-effects after commencing ART. The most prevalent side-effect experienced by St Apollinaris respondents was rash (49.16%, n=117). This could be due to both Efavirenz (EFV) and Stavudine (d4T) in the first-line regimen (see Table 5.16). Respondents at Hope for Life (68.12%, n=94) and Bela-Bela (32.04%, n=33) mostly complained about peripheral neuropathy, a side –effect mostly caused by Stavudine (d4T). Respondents (38.97%, n=53) at Tapologo complained about non-specific side-effects (like nausea, fatigue and "not feeling well"). Although none of these side-effects are life-threatening they cause severe distress for the individual experiencing it.

Table 5.18 Side effects

	Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Experienced	Yes	**73.46% (n=238)**	**65.71% (n=138)**	**47.39% (n=136)**	**55.68% (n=103)**	**61.13% (n=615)**
	No	26.54% (n=86)	34.29% (n=72)	52.61% (n=151)	44.32%(n=82)	38.87% (n=391)
Side-effects	**PN***	24.79% (n=59)	**68.12% (n=94)**	13.24% (n=18)	**32.04% (n=33)**	33.17% (n=204)
	Rash	**49.16% (n=117)**	17.39% (n=24)	17.65% (n=24)	10.68% (n=11)	28.62% (n=176)
	Non-specific	16.81% (n=40)	36.95% (n=51)	**38.97% (n=53)**	28.15% (n=29)	28.13% (n=173)
	Nightmares	28.15% (n=67)	7.25% (n=10)	25.74% (n=35)	18.45% (n=19)	21.30% (n=131)
	Headache	21.85% (n=52)	10.14% (n=14)	20.59% (n=28)	20.39% (n=21)	18.70% (n=115)
	Insomnia	7.14% (n=17)	3.62% (n=5)	19.85% (n=27)	3.88% (n=4)	8.62% (n=53)
	Anemia	1.26% (n=3)	1.45% (n=2)	2.21% (n=3)	8.74% (n=9)	2.76% (n=17)
	Liver	0.00% (n=0)	0.00% (n=0)	1.47% (n=2)	0.00% (n=0)	0.33% (n=2)
	HL*	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.97% (n=1)	0.16% (n=1)

* HL = Hyper lactatemia, *PN = Peripheral neuropathy

In some cases side-effects will necessitate treatment disruption or regimen changes.

5.4.7. Treatment disruption or regimen changes

Indications for the disrupting or changes in treatment regimens include drug toxicity, drug intolerance and treatment failure. Table 5.19 reflects the recorded treatment disruptions and regimen changes obtained from the file audits. A small group (7.51%, n=75) of the respondents' treatment was disrupted, while more than a fifth (22.60%, n=224) of the respondents had a regimen change.

Table 5.19 Recorded regimen disruption or changes

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Rx disruption	Yes	6.19% (n=20)	3.86% (n=8)	8.10% (n=23)	12.97% (n=24)	7.51% (n=75)
	No	**93.81% (n=303)**	**96.14% (n=199)**	**91.90% (n=261)**	**87.03% (n=161)**	**92.49% (n=924)**
Rx changes	Yes	3.40% (n=11)	36.63% (n=74)	8.80% (n=25)	62.29% (n=114)	22.60% (n=224)
	No	**96.60% (n=313)**	**63.37% (n=128)**	**91.20% (n=259)**	**37.02% (n=67)**	**77.40% (n=767)**

Treatment disruptions occur for different reasons. A HCW can decide to disrupt treatment because of life-threatening side-effects, like hyperlactatemia (a potentially fatal complication where the patient's venous lactate level rise to a level >2mM) (Foundation for Professional Development, 2010: 160, Barlett and Gallant, 2003: 84) or due to very poor adherence. Patients might also decide to discontinue treatment for a variety of reasons as indicated in Table 5.20.

Table 5.20 Treatment disruption

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Disruption	Yes	4.32% (n=14)	1.43% (n=3)	5.57% (n=16)	2.70% (n=5)	3.78% (n=38)
	No	**95.68% (n=310)**	**98.57% (n=207)**	**94.43% (n=271)**	**97.30% (n=180)**	**96.22% (n=968)**
Reason for disruption	Side effects	**50.00% (n=7)**	**66.67% (n=2)**	**31.25% (n=5)**	**60.00% (n=3)**	**44.74% (n=17)**
	Other	21.43% (n=3)	0.00% (n=0)	25.00% (n=4)	0.00% (n=0)	18.42% (n=7)
	Adherence	7.14% (n=1)	0.00% (n=0)	12.50% (n=2)	40.00% (n=2)	13.16% (n=5)
	TB	14.29% (n=2)	0.00% (n=0)	12.50% (n=2)	0.00% (n=0)	10.53% (n=4)
	Rx Failure	0.00% (n=0)	0.00% (n=0)	12.50% (n=2)	0.00% (n=0)	5.26% (n=2)
	Choice	0.00% (n=0)	0.00% (n=0)	6.25% (n=1)	0.00% (n=0)	2.63% (n=1)
	New drug	7.14% (n=1)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	2.63% (n=1)
	Pregnancy	0.00% (n=0)	33.33% (n=1)	0.00% (n=0)	0.00% (n=0)	2.63% (n=1)

The structured interview schedule did not distinguish between HCW and patient choice concerning discontinuing of treatment. Fewer disruptions were identified with the structured interview than with the audit of the files. Although patients are requested not to disrupt treatment due to side-effects, it was the main reason for disruption of treatment. Patients are advised rather to seek help when they experience side-effects, because in some cases the regimen can be changed.

A decision to change treatment for toxicity should be based on the severity. For both toxicity and intolerance the drug should be switched for a drug with the same potency from the same class (Wilson and Fairall, 2010: 546). Limited regimen changes are allowed within the National guidelines. These changes are made in the case of severe side-effects (toxicity), intolerance, pregnancy and TB. A confirmed VL of greater than 5000 copies/mL after adherence intensification is considered as treatment failure and is justification for change to a second regimen (Wood and Martin, 2008: 279).

Nearly a quarter (24.06%, n=242) of the respondents reported that their regimens were changed as tabulated in Table 5.21. At St Apollinaris (8.02%, n=26) and Tapologo (10.10%, n=29) notably fewer respondents changed their regimens than at Hope for Life (42.86%, n=90) and Bela-Bela (52.43%, n=97). This might be due to a more pro-active approach at these projects.

Table 5.21 ART regimen change

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Changed	Yes	8.02% (n=26)	42.86% (n=90)	10.10% (n=29)	**52.43% (n=97)**	24.06% (n=242)
	No	**91.98% (n=298)**	**57.14% (n=120)**	**89.90% (n=258)**	47.57%(n=88)	**75.94% (n=764)**
Reason for change	Side effects	15.38% (n=4)	**75.56% (n=68)**	**31.03% (n=9)**	**57.73% (n=56)**	**56.61% (n=137)**
	Other	**26.92% (n=7)**	5.56% (n=5)	6.90% (n=2)	19.59% (n=19)	13.64% (n=33)
	Pregnancy	3.85% (n=1)	4.44% (n=4)	**31.03% (n=9)**	11.34% (n=11)	10.33% (n=25)
	Rx Failure	3.85% (n=1)	0.00% (n=0)	10.34% (n=3)	6.19% (n=6)	4.13% (n=10)
	Adherence	3.85% (n=1)	1.11% (n=1)	6.90% (n=2)	4.12% (n=4)	3.31% (n=8)
	New drug	3.85% (n=1)	3.33% (n=3)	3.45% (n=1)	1.03% (n=1)	2.48% (n=6)
	TB	11.54% (n=3)	0.00% (n=0)	6.90% (n=2)	1.03% (n=1)	2.48% (n=6)
	Toxicity	7.69% (n=2)	2.22% (n=2)	0.00% (n=0)	1.03% (n=1)	2.07% (n=5)
	Stock-out	3.85% (n=1)	3.33% (n=3)	0.00% (n=0)	0.00% (n=0)	1.65% (n=4)
	Pt. choice	0.00% (n=0)	1.11% (n=1)	0.00% (n=0)	0.00% (n=0)	0.41% (n=1)

Respondents were asked what regimen they were changed to. At St Apollinaris and Bela-Bela the use of Zidovudine (ZDV) increased (n=6 and n=88). While at Hope for Life and Tapologo the use of Combivir (ZDV + 3TC) increased (n=59 and n=14). Essentially the same changes were made. Hope for Life and Tapologo just used the fixed dose combination of the antiretroviral agents. The use of Didanosine (DDI) and Lopinavir/Ritonavir (LPV/r) did not increase much (0.42% and 1.68%), indicating that the respondents were not put on the recommended second-line regimens. Stavudine (d4T) was thus changed for Zidovudine (ZDV), a drug from the same class.

In a study based in Khayelitsha, 84.9% of patients were still on first-line regimen after 24 months. In the Khayelitsha group regimen changes were made for 8.8% of the patients from Nevirapine (NVP) to Efavirenz (EFV) due to adverse effects, 4.7% of patients on Zidovudine changed to Stavudine due to side effects, and 2.87% patients changed to Efavirenz due to the need to start TB treatment containing rifampicin (Coetzee *et al*, 2005: 892). The picture in the SACBC projects looked very different, possibly due to cost-saving measures in place. Wood and Martin (2008: 283), however, attributed switches from Stavudine (d4T) after 6 months on treatment to lipodystrophy and peripheral neuropathy. This could well be one of the leading causes of regimen change as 204 (33.17%) respondents (see Table 5.18) complained of peripheral neuropathy while 137 (56.61%) respondents (see Table 5.21) listed the reason for regimen change as side-effects.

Experiencing side-effects does not only contribute to regimen changes but could also negatively affect adherence.

5.5. Adherence

Adherence is defined as taking the correct dose of drugs at the correct time and in the correct way (CAFOD, 2008: 5). An acceptable level of adherence to therapy in chronic illness is consumption of more than 80% of the prescribed doses (Paterson *et al*, 2000: 27). Higher levels of adherence are needed in HIV management than in other chronic illnesses to be a good predictor of treatment success and outcome (Sherr *et al*, 2008: 442). Paterson *et al* (2000: 27, 28) have shown that patients with 95% or greater adherence had a superior virological outcome, a greater increase in CD4 cells, and lower hospitalization rate than did patients with lower levels of adherence. This equates to missing no more than three doses a month, year after year (CAFOD, 2008: 6).

More recent studies suggest that there is a difference between the relationship between adherence, viral suppression and viral resistance for antiretroviral agents from the NNRTI and PI classes. NNRTI treated individuals were significantly more likely to have evidence of viral suppression to undetectable values than PI-treated individuals. However, NNRTI treated individuals have significantly higher levels of resistance at low levels of adherence than individuals treated with PIs (Bangsberg *et al*, 2006: 226). High levels of adherence were significantly associated with improved viral suppression in individuals regardless of the class of drugs taken (Bangsberg *et al*, 2006: 226). Maintaining good levels of adherence is therefore paramount regardless of the antiretroviral agents the individual is taking.

Adherence at desired levels might not be difficult to achieve during the early stages of therapy particularly considering the elevated patient motivation, the emotional distress associated with the recent diagnosis, the perceived threat to the patient's own health and the simplicity of first-line regimens. However, adherence may progressively decrease thereafter due to a gradual relaxation of these attitudes, a decrease in motivation and a perceived lowering of threat from the illness. Asymptomatic periods and ART-induced changes in body fat distribution, metabolic alterations and other long-term toxicities during the disease can demotivate adherence (Paredes, Sherer and Clotet, 2008: 422). Therefore adherence support should be integrated into standard care (Paredes, Sherer and Clotet, 2008: 428). Adherence to ART is usually complex and long-term adherence can be difficult to achieve (Peretti-Watel *et al*, 2006: 254). Various factors influence adherence.

5.5.1. Influences on adherence

Adherence is affected by different factors related to the patient, the medication and the system of care (National Department of Health, South Africa, 2010: 17; Kent *et al*, 2003: 19; Chesney, 2000: 172). Patient factors include active substance abuse, gender (male), age (youth), lower levels of education, mental illness (depression, anxiety and dementia), internalized stigma, external discrimination, denial of diagnosis, unresolved grief reaction, lack of disclosure, guilt, pain, no change in health status, income and food security. Medication factors include dose frequency, pill burden, type of drug, drug interactions, food requirements and side effects. System of care factors include dissatisfaction with past experience of healthcare system, poor health provider – patient relationship, perceived lack of caring by health facility and staff, negative staff attitudes, lack of training of staff, accessibility of services (see Chapter Four) and lack of time to attend appointments. ART projects should focus on multipronged interventions that can increase adherence.

Kent *et al* (2003: 19) suggested various interventions that could increase adherence. Patient-focused interventions include education, cues and reminders, involvement in therapeutic plans, rewards and reinforcement (improved health, CD4 tests, etc.), social support or extended supervision and treatment of depression, substance abuse and co-morbid conditions. Drug-focused interventions include decreasing daily frequency of dosing, decreasing pill burden, improving taste of agents, using agents with fewer side-effects and decreasing cost Provider-focused interventions influencing the system of care include the continuation of medical education, provision of additional support (task-shifting) and the availability of aids to enhance adherence.

Various methods of determining adherence are available.

5.5.2. Determining adherence

Biological markers such as VL testing are the best measure of virological failure; however, the technology is not always freely available (Sherr *et al*, 2008: 443). Other methods range from staff judgments to electronic drug monitoring (EDM) and pill counts, to self-reported adherence.

Table 5.22 Staff judgment of adherence

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Adherence problems	Yes	39.75% (n=128)	46.86% (n=97)	13.12% (n=37)	21.20% (n=39)	30.25% (n=301)
	No	**60.25% (n=194)**	**53.14% (n=110)**	**86.88% (n=245)**	**78.80% (n=145)**	**69.75% (n=694)**

Staff recorded that nearly a third (30.25%, n=301) of the respondents had adherence problems as demonstrated in Table 5.22. These figures might not be a true indication as a study by Paterson *et al* (2000: 26) concluded that HCWs misjudged the degree of adherence in 41% of their patients, making staff judgments unreliable.

Electronic drug monitoring utilizes monitoring devices (such as the Medication Event Monitoring System cap) which is a pill-bottle cap embedded with a microprocessor that records the time and date of each bottle opening and presumptive dose (Berg and Arnsten, 2006: 4). Although EDM is more sensitive than self-reported measures, it is not feasible outside research settings (Arnsten *et al*, 2001: 6)

Pill counts take place at clinical appointments or scheduled research visits to which individuals brings their medication bottles (Berg and Arnsten, 2006: 5). Unannounced pill counts seem to be more reliable than announced pill counts as they prevent pill dump prior to assessment (Bangsberg *et al*, 2003: 1926). Due to the associated methodological challenges and potential impact on the patient-provider relationship, pill counting is, however, poorly situated in assessing adherence in clinical settings. Most importantly, patients may perceive pill counting as threatening and suggestive of lack of trust in their self-reported adherence (Berg and Arnsten, 2006: 5).

Self-reported adherence is commonly used due to its simplicity and low cost (Blacher *et al*, 2010: 1324; Sherr *et al*, 2008: 443). Individuals are requested to recall their adherence over a particular period. Recall over 7 days provides a partial snapshot of adherence (Sherr *et al*, 2008: 447). Self-reported adherence might be subject to recall bias and the individual's reluctance to report poor adherence (Blacher *et al*, 2010: 1323). Watt *et al* (2010: 384) and Mellins *et al* (2009: 174), however, found that self-reported adherence consistently correlated with VL. It is therefore a reliable long-term follow-up method (Ubbiali *et al*, 2008: 574; Sethi *et al*, 2003: 1116). Furthermore, self-report is the most commonly used adherence measure in both clinical and research settings because it has low staff respondent burden, and is inexpensive, flexible, and takes very little time. It also allows for discussion of reasons for missed doses and potential solutions (Berg and Arnsten, 2006: 2). Table 5.23 shows the frequency of self-reported missed doses by respondents. The median for all four of the projects was zero. This provides a very different view than that of Table 5.22.

Table 5.23 Self-reported missed doses

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Missed doses	Minimum	0	0	0	0	0
	Median	0	0	0	0	0
	Maximum	21	21	10	35	35

Respondents were further asked what would be possible reasons for missing doses. The reasons are tabulated in Table 5.24. The main reasons for missing doses reported by respondents were being away from home (22.07%, n=222), being busy (21.27%, n=214) or falling asleep (12.82%, n=129). Mellins *et al* (2009: 172) reported reasons for missing doses as: falling asleep (49%), busy (45%), away from home (43%) and a change in routine (39%). Others found that the individuals simply forgot (Watt *et al*, 2010: 384; Murray *et al*, 2009: 78). Avoiding treatment due to side-effects was also recorded for individuals as high as 60% (Nellen *et al*, 2009: 845), but in this study only 3% (n=30) mentioned side-effects as a reason for not taking the medication. Aspects to take into consideration are those that may have negative influence on adherence, for example that they ran out of medication, viewed ART as harmful and that they no longer needed it.

Table 5.24 Reason for missing doses

Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Away from home	**15.43% (n=50)**	**20.48% (n=43)**	**24.39% (n=70)**	**31.89% (n=59)**	**22.07% (n=222)**
Busy	**18.83% (n=61)**	**24.29% (n=51)**	**18.47% (n=53)**	**26.49% (n=49)**	**21.27% (n=214)**
Fell asleep	5.56% (n=18)	13.81% (n=29)	**16.38% (n=47)**	**18.92% (n=35)**	**12.82% (n=129)**
Change in routine	**11.11% (n=36)**	**21.90% (n=46)**	7.67% (n=22)	6.49% (n=12)	11.53% (n=116)
Too ill	4.01% (n=13)	4.76% (n=10)	10.10% (n=29)	7.57% (n=14)	6.56% (n=66)
Depressed	2.47% (n=8)	4.76% (n=10)	12.20% (n=35)	4.86% (n=9)	6.16% (n=62)
Nondisclosure	4.01% (n=13)	2.86% (n=6)	7.67% (n=22)	1.62% (n=3)	4.37% (n=44)
ART finished	4.94% (n=16)	4.76% (n=10)	1.74% (n=5)	2.16% (n=4)	3.48% (n=35)
Pill burden	2.78% (n=9)	1.91% (n=4)	6.27% (n=18)	1.62% (n=3)	3.38% (n=34)
Side effects	*2.47% (n=8)*	*5.24% (n=11)*	*3.83% (n=11)*	*0.00% (n=0)*	*2.98% (n=30)*
ART harmful	*1.54% (n=5)*	*3.81% (n=8)*	*2.79% (n=8)*	*0.54% (n=1)*	*2.19% (n=22)*
No need for ART	*0.93% (n=3)*	*2.38% (n=5)*	*2.79% (n=8)*	*0.00% (n=0)*	*1.60% (n=16)*

Respondents were questioned about what was helpful to remind them to take their ART (adhere). Responses were grouped together by theme: the number of responses could therefore be higher than the number of respondents. Respondents could give more than one response. The majority of respondents (91.25%, n=918) used some type of alarm to remind themselves to take their ART on time. Treatment buddies (25.45%, n=256), routine (15.61%, n=157) and the respondents themselves (6.96%, n=70) were also helpful as tabulated in Table 5.25.

Table 5.25 Helpful to remember to take ART

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Alarm	**88.89% (n=288)**	**127.14% (n=267)**	**77.35% (n=222)**	**76.22% (n=141)**	**91.25% (n=918)**
Buddy/Family	**34.26% (n=111)**	**18.57% (n=39)**	**21.60% (n=62)**	**25.41% (n=47)**	**25.45% (n=256)**
Routine	**13.58% (n=44)**	**8.10% (n=17)**	17.07% (n=49)	**23.78% (n=44)**	**15.61% (n=157)**
Self	4.32% (n=14)	1.90% (n=4)	**17.77% (n=51)**	0.54% (n=1)	6.96% (n=70)
Health	0.00% (n=0)	0.00% (n=0)	5.23% (n=15)	4.32% (n=8)	2.29% (n=23)
Write down	0.31% (n=1)	0.48% (n=1)	3.48% (n=10)	0.00% (n=0)	1.19% (n=12)
Carry tablets	1.54% (n=5)	0.48% (n=1)	0.70% (n=2)	1.62% (n=3)	1.09% (n=11)
No response	0.31% (n=1)	0.00% (n=0)	1.05% (n=3)	0.54% (n=1)	0.50% (n=5)

Berg *et al* (2005: 906) found appointment non-adherence was associated with medication non-adherence.

5.5.3. Missing visits

Missing a scheduled visit by more than eight days is associated with virological failure (Blacher *et al*, 2010: 1323; Watt *et al*, 2010: 381). There is a link between self-reported adherence, timeliness to scheduled visits and ultimately virological failure (Blacher *et al*, 2010: 1323). These make the reasons respondents miss doses important (see Table 5.24). Watt *et al* (2010: 384) found that patients ran out of medication due to missing their scheduled visits, highlighting the need to pay attention to the reasons given for missing a dose as recorded in Table 5.24.

Missing a visit is further associated with having both a detectable VL and having an AIDS-defining CD4 count (Berg *et al*, 2005: 904). Sethi *et al* (2003: 1117) found some individuals who reported a 100% adherence as having drug resistance; these individuals had more missed scheduled visits than the individuals who reported non-adherence or those who did not develop resistance. It is therefore vital that clinic staff assess the underlying reasons for missed scheduled visits and find ways to improve clinic attendance rates (Sethi *et al*, 2003: 1118).

Table 5.26 Missed visits

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Missed	Yes	14.20% (n=46)	**10.48% (n=22)**	12.54% (n=36)	**9.73% (n=18)**	12.13% (n=122)
	No	85.80% (n=278)	89.52% (n=188)	87.46% (n=251)	90.27%(n=167)	87.87% (n=884)
Number of appointments	Minimum	1.00	0.00	1.00	1.00	0.00
	Median	1.00	1.00	1.00	1.00	1.00
	Maximum	4.00	2.00	8.00	5.00	8.00
Contact made	Yes	2.38% (n=1)	**18.18% (n=4)**	52.94% (n=18)	**33.33% (n=6)**	25.00% (n=29)
	No	97.62% (n=41)	81.82% (n=18)	47.06% (n=16)	66.67%(n=12)	75.00% (n=87)

Table 5.26 indicates the visits missed by respondents. Overall 122 (12.13%) of the respondents reported that they had missed a scheduled visit. The median number of visits missed was one. Only a quarter (25.00%, n=29) of the respondents were contacted by project staff to ask why they had missed their visit.

Respondents were asked why they had missed their visits. Table 5.27 illustrates a varied picture. St Apollinaris respondents (50.00% who missed a visit, n=23) had trouble with transport; this was also reflected in Table 4.5. Employment played a large role at Hope for Life (31.82%, n=7), Tapologo (25.00%, n=9), Bela-Bela (22.22%, n=4) and St Apollinaris (15.22%, n=7). Once the respondents' health improves the hope is that they would be able to continue or gain employment.

The operation hours of the facilities are troublesome as seen in Table 4.3. The facilities are open in business hours, meaning a patient has to take time off work to honor a visit. At Bela-Bela a third (33.33%, n=6) of the respondents who had missed a visit responded that they were away from the area. Table 4.9 illustrated that 23.78% (n=44) of the respondents were away from the area for more than a week in the past year. Another third (33.33%, n=6) of the Bela-Bela respondents simply forgot. Noticeably transport was not a problem at Bela-Bela.

Table 5.27 Reasons for missing visits

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Transport	**50.00% (n=23)**	4.55% (n=1)	13.89% (n=5)	0.00% (n=0)	**23.77% (n=29)**
Away	6.52% (n=3)	4.55% (n=1)	13.89% (n=5)	**33.33% (n=6)**	**22.95% (n=28)**
Employment	**15.22% (n=7)**	**31.82% (n=7)**	**25.00% (n=9)**	22.22% (n=4)	22.13% (n=27)
Family	6.52% (n=3)	4.55% (n=1)	**22.22% (n=8)**	5.56% (n=1)	13.11% (n=16)
No response	6.52% (n=3)	**40.91% (n=9)**	0.00% (n=0)	0.00% (n=0)	9.84% (n=12)
Forgot	2.17% (n=1)	9.09% (n=2)	0.00% (n=0)	**33.33% (n=6)**	7.38% (n=9)
Health	4.35% (n=2)	0.00% (n=0)	8.33% (n=3)	5.56% (n=1)	4.92% (n=6)
Other	2.17% (n=1)	4.55% (n=1)	11.11% (n=4)	0.00% (n=0)	4.92% (n=6)
Still have ART	6.52% (n=3)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	2.46% (n=3)
Side-effects	0.00% (n=0)	0.00% (n=0)	5.56% (n=2)	0.00% (n=0)	1.64% (n=2)

Respondents indicated in Table 5.28 that writing down the visit date, either on a patient card (45.92%, n=462) or in a calendar or book (41.75%, n=420), was the most useful to remind them of their visit date. When asked which single intervention was most useful the respondents provided answers which correlated with information in the figures reflected in Table 5.28.

Table 5.28 Techniques as reminders of scheduled visit

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Pt. card	22.53% (n=73)	**70.00% (n=147)**	46.69% (n=134)	**58.38% (n=108)**	**45.92% (n=462)**
Write down	**38.27% (n=124)**	38.57% (n=81)	**53.66% (n=154)**	32.97% (n=61)	41.75% (n=420)
Buddy/Family	29.63% (n=96)	28.10% (n=59)	18.12% (n=52)	12.43% (n=23)	22.86% (n=230)
Pill box	18.83% (n=61)	8.10% (n=17)	19.86% (n=57)	31.89% (n=59)	19.28% (n=194)
Self	14.81% (n=48)	11.90% (n=25)	12.54% (n=36)	14.59% (n=27)	13.52% (n=136)
Cellphone	4.01% (n=13)	11.43% (n=24)	12.89% (n=37)	9.73% (n=18)	9.15% (n=92)
Staff	0.00% (n=0)	4.76% (n=10)	3.48% (n=10)	2.70% (n=5)	2.49% (n=25)
Routine	0.31% (n=1)	0.95% (n=2)	4.88% (n=14)	1.08% (n=2)	1.89% (n=19)
No response	4.63% (n=15)	0.00% (n=0)	0.35% (n=1)	0.00% (n=0)	1.59% (n=16)
Health	0.00% (n=0)	0.00% (n=0)	0.70% (n=2)	0.00% (n=0)	0.20% (n=2)

Non-adherent patients may experience deterioration in biological variables and a worsening of symptoms and functional status (Duggan *et al*, 2009: 1146). ART patients should therefore be monitored closely for outcome.

5.6. Outcome

Three different measures will be discussed to describe the treatment outcome of the respondents. The biological variables measuring viral suppression, cell-mediated immunity and body mass index (BMI) will be described, followed by the respondents' self-perceived QOL and hospitalizations since initiation of ART.

Respondents were grouped in cohorts to establish the time on ART. These cohorts are reflected in Table 5.29. The largest group (44.93%, n=452) of the respondents can be found in the 0-12 month's cohort. The 0-3 month's cohort is part of the 0-12 month's cohort. St Apollinaris had fewer (1.23%, n=4) respondents in the 37-48 month's cohort.

Table 5.29 Time on ART

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Time (in months)	0-3	16.05% (n=52)	17.14% (n=36)	17.77% (n=51)	12.97% (n=24)	16.20% (n=163)
	0-12	**51.85% (n=168)**	**41.43% (n=87)**	**46.69% (n=134)**	**34.05% (n=63)**	**44.93% (n=452)**
	13-24	30.86% (n=100)	23.81% (n=50)	19.86% (n=57)	22.70% (n=42)	24.75% (n=249)
	25-35	15.43% (n=50)	20.95% (n=44)	20.21% (n=58)	29.73% (n=55)	20.58% (n=207)
	37-48	1.23% (n=4)	**13.81% (n=29)**	**13.24% (n=38)**	**13.51% (n=25)**	**9.54% (n=96)**
	49 +	0.62% (n=2)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.20% (n=2)

Favorable responses to ART include a decline in plasma HIV RNA and an increase in CD4 cell counts.

5.6.1. Biological variables

Favorable responses to ART include a decline in plasma HIV RNA and an increase in CD4 cell counts. Reduction of plasma viremia achieved by ART is the most important outcome. The correlation between CD4 cell count and Viral Load (VL) is weak in many patients; however, continued viral suppression is positively associated with an increase in CD4 cell count (Wilson and Fairall, 2010: 531). A quantitative plasma HIV RNA PCR assay (often referred to as a VL) is taken to determine if the goal of ART, to achieve viral suppression to a level where the virus can no longer be detected, has been achieved (Evian, 2006: 27; Mayer and Cohen, 2003: 711). Table 5.30 reflects the median VL of the respondents with the lower and upper quartile in parenthesis. The median VL at two to three months on treatment is already undetectable indicating a good viral response. The results for St Apollinaris are different as they use a different laboratory system (see section 4.5). All the projects had good viral suppression of their respondents.

Bekker *et al* (2003: 462) also found that viral response data demonstrated that an ART project can be initiated successfully outside tertiary care facilities.

Table 5.30 Viral loads of respondents

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
VL	Base	75,000 [3,200:250,000]	60,741 [18,949:198,445]	68,461 [20,886:209,229]	67,995 [22,886:170,604]
	2,3 mo	<25 [<25:66,000]	<50 [<50:<50]	<50 [<50:114]	<50 [<50:74]
	6 mo	<25 [<25:<25]	<50 [<50:<50]	<50 [<50:<50]	<50 [<50:<50]
	12 mo	<25 [<25:72]	<50 [<50:<50]	<50 [<50:<50]	<50 [<50:<50]
	18 mo	<25 [<25:<25]	<50 [<50:<50]	<50 [<50:<50]	<50 [<50:<50]
	24 mo	<25 [<25:70]	<50 [<50:<50]	<50 [<50:<50]	<50 [<50:<50]
	30 mo	<25 [<25:<25]	<50 [<50:<50]	<50 [<50:<50]	<50 [<50:<50]
	36 mo	<25 [<25:<25]	<50 [<50:<50]	<50 [<50:55]	<50 [<50:<50]

Mo = months on ART. The 48+ month data are omitted due to the small sample. Table reflects median VL of the respondents with the lower and upper quartile in parenthesis. St Apollinaris uses a different laboratory service and the undetectable VL is indicated as <25, while it is <50 at the NGO sites.

A CD4 T-lymphocyte count (often referred to as the CD4 count) is the most readily available quantitative measure of the status of the cell-mediated immune system (Evian, 2006: 26; Mayer and Cohen, 2003: 711). The median CD4 count of the respondents is shown in Table 5.31.

Table 5.31 CD4 counts of respondents

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
CD4 count	Base	118 [68:185]	116 [61:192]	121 [54:201]	124 [51:205]
	2,3 mo	234 [176:332]	245 [161:339]	186 [128:345]	244 [137:376]
	6 mo	240 [179:317]	246 [162:325]	280 [174:394]	235 [152:369]
	12 mo	240 [137:341]	293 [203:391]	340 [251:474]	310.5 [200:426]
	18 mo	311 [210:393]	367 [255:502]	416 [269:537]	416 [228:559]
	24 mo	383 [257:521]	370 [295:502]	410 [295:574]	406 [282:591]
	30 mo	368 [261:469]	394 [255:501]	410 [267:673]	467 [242:598]
	36 mo	634 [376:764]	416 [241:537]	533 [309:729]	408 [254:570]

mo = months on ART. The 48+ month data are omitted due to the small sample. Table reflects median CD4 count of the respondents with the lower and upper quartile in parenthesis.

All the median CD4 counts demonstrate a steady and continuing increase in CD4 count response to ART over time.

These positive outcomes have been demonstrated in other South African programs. Coetzee *et al* (2005: 893) also described the high proportion of patients with an undetectable VL in the first year on treatment, underlining that adherence rates compare to those of high-income countries. In a comparison between low- and high-income countries, Dabis *et al* (2006: 817) found that the low-income countries' patients who had lower CD4 cell counts (median 108 cells/mm^3 vs. 234 cells/mm^3) were more likely to be female (51% vs. 25%) and more likely to start on a NNRTI containing regimen (70% vs. 23%). Similar viral suppression could be achieved after six months on treatment, but the mortality rates in the low-income countries were higher. Mortality rates and HIV progression decreases as the BMI increases (Jones *et al*, 2003: 69).

Table 5.32 Body Mass Index of respondents

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela
BMI	Base	22.02 [19.68:25.23]	21.51 [19.28:24.90]	20.57 [17.47:23.53]	20.13 [18.08:22.57]
	2,3 mo	22.64 [20.57:25.77]	22.31 [20.08:25.72]	21.23 [18.52:24.97]	21.18 [19.14:23.59]
	6 mo	23.74 [21.67:26.99]	23.80 [20.55:26.78]	22.45 [19.21:26.85]	21.77 [20.13:24.98]
	12 mo	24.22 [21.78.27.63]	23.94 [20.96:27.06]	22.70 [19.90:27.59]	22.27 [20.42:24.82]
	18 mo	**24.17** [21.63:27.29]	**23.23** [20.99:26.17]	23.60 [20.15:27.59]	**21.88** [20.20:24.78]
	24 mo	23.86 [20.73:26.62]	23.53 [21.52:26.40]	23.60 [19.64:27.11]	**21.63** [19.92:24.80]
	30 mo	22.75 [20.08:26.67]	**23.12** [20.58:29.67]	**23.26** [19.87:26.67]	21.75 [19.11:24.24]
	36 mo	26.50 [20.93:26.84]	No data	**23.01** [21.11:27.78]	**22.21** [20.17:24.75]

mo = months on ART. The 48+ month data are omitted due to the small sample. Table reflects median BMI of the respondents with the lower and upper quartile in parenthesis.

BMI is a formula for determining obesity (in this case underweight). It is calculated by dividing a person's weight in kilograms by the square of the person's height in meters (Mosby, 1998: 211). Patients are classified as underweight (BMI < 18·5), normal (18·5 ≤ BMI < 25), overweight (25 ≤ BMI < 30) or obese (BMI ≥ 30) (Resepo *et al*, 2011: online). Table 5.32 demonstrates the increase of BMI as the respondents gained weight. The majority of the respondents were found to be within the normal range (18·5 ≤ BMI < 25) with some respondents on the lower quartile at Tapologo and Bela-Bela under 18.5 at base (initiation of ART). All the respondents were within the normal range at two to three months on ART. Respondents on the upper quartile showed signs of being overweight by six months on ART. Weight gain after ART initiation has been reported in other settings (Visser, 2010: 492). A plateau-effect can be seen after 18 month on treatment in Table 5.32. Boodram *et al* (2009: 1014) argued that after the initial gain in fat due to a restoration to health, longer duration of antiretroviral agents (particularly Stavudine and Zidovudine) could be associated with lipoatrophy, explaining the drop in body weight. Table 5.16 reflected extensive use of Stavudine and Zidovudine.

Monitoring the biological variables of patients is important, but ultimately the ART patients' QOL should improve. Health is a state of complete physical, mental and social well-being and not merely the absence of disease (World Health Organization, 1948: online). In general, patients on ART experienced significant improvements in number of symptoms, overall health, and overall QOL. QOL is an indication of the patients' wellbeing as QOL improves for patients who experienced improved symptoms and with the unchanged or worsening symptoms QOL decreased (Lorenz *et al*, 2006: 953).

5.6.2. Quality of life

Important determinants of QOL may include symptoms, medication-related factors, including adherence and tolerability, social support, and behavioral characteristics (Viswanathan, Anderson and Thomas, 2005: 941).

To introduce the topic of QOL the respondents were asked if they perceived themselves as sick. Table 5.33 reflects that just over a third (34.19%, n=344) of the respondents perceived themselves as ill.

Table 5.33 Respondents who consider themselves currently ill

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Yes	**42.90% (n=139)**	22.38% (n=47)	**42.16% (n=121)**	20.00% (n=37)	34.19% (n=344)
No	57.10% (n=185)	77.62% (n=163)	57.84% (n=166)	80.00% (n=148)	65.81% (n=662)

Respondents at St Apollinaris and Tapologo perceived themselves more ill than those at Hope for Life and Bela-Bela. When asked about the nature of the illness the majority of respondents complained about pain (53.20%, n=183), followed by the experience of side-effects (26.45%, n=91) and possible TB-related respiratory problems (21.80%, n=75) as indicated in Table 5.34.

Table 5.34 Current illness

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Pain	62.59%(n=87)	48.94%(n=23)	50.41%(n=61)	32.43%(n=12)	53.2%(n=183)
Side-effects	25.90%(n=36)	40.43%(n=19)	21.49%(n=26)	27.03%(n=10)	26.45%(n=91)
Respiratory system (?TB)	23.02%(n=32)	25.53%(n=12)	18.18%(n=22)	24.32%(n=9)	21.80%(n=75)
Miscellaneous	11.51%(n=16)	10.64%(n=5)	25.62%(n=31)	13.51%(n=5)	16.57%(n=57)
Flu	3.60%(n=5)	10.64%(n=5)	12.40%(n=15)	21.62%(n=8)	9.59%(n=33)
GI symptoms	11.51%(n=16)	2.13%(n=1)	2.48%(n=3)	18.92%(n=7)	7.85%(n=27)
Malaise	7.91%(n=11)	8.51%(n=4)	2.48%(n=3)	16.22%(n=6)	6.98%(n=24)
Cardiac	0.72%(n=1)	0.00%(n=0)	5.79%(n=7)	5.41%(n=2)	2.91%(n=10)
ENT symptoms	1.44%(n=2)	2.13%(n=1)	4.13%(n=5)	2.70%(n=1)	2.62%(n=9)
Nervous system	0.00%(n=0)	4.26%(n=2)	2.48%(n=3)	8.11%(n=3)	2.33%(n=8)
Herpes Zoster	2.88%(n=4)	0.00%(n=0)	2.48%(n=3)	0.00%(n=0)	2.03%(n=7)
Urinary system	0.00%(n=0)	2.13%(n=1)	2.48%(n=3)	0.00%(n=0)	1.16%(n=4)
Cancer	0.72%(n=1)	2.13%(n=1)	0.00%(n=0)	0.00%(n=0)	0.58%(n=2)
STI	0.00%(n=0)	0.00%(n=0)	0.83%(n=1)	0.00%(n=0)	0.29%(n=1)
No response	0.72%(n=1)	0.00%(n=0)	0.00%(n=0)	0.00%(n=0)	0.29%(n=1)

ENT = Ear, nose and throat

With worse experiences of illness at St Apollinaris and Tapologo it could be expected that these respondents experience their QOL lower than that of those as at Hope for Life and Bela-Bela. Subjective experience of adverse effects can be a strong predictor of the deterioration in emotional QOL (Eriksson *et al*, 2005: 6). With single exceptions this did not seem to be the case as reflected in Table 5.35.

Table 5.35 QOL on five dimensions

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
No problems	Mobility	75.62% (n=245)	79.05% (n=166)	68.64% (n=197)	69.73% (n=129)	73.26% (n=737)
	Self-care	95.37% (n=309)	98.10% (n=206)	95.47% (n=274)	94.592% (n=175)	95.83% (n=964)
	Usual activity	**56.48% (n=183)**	74.29% (n=156)	71.43% (n=205)	81.62% (n=151)	69.09% (n=695)
	Pain	**53.70% (n=174)**	65.71% (n=138)	**45.99% (n=132)**	**57.30% (n=106)**	54.67% (n=550)
	Anxiety, Depres.	66.36% (n=215)	72.86% (n=153)	60.63% (n=174)	75.68% (n=140)	67.79% (n=682)
Some problems	Mobility	24.38% (n=79)	20.95% (n=44)	31.01% (n=89)	30.27% (n=56)	26.64% (n=268)
	Self-care	4.32% (n=14)	1.90% (n=4)	4.53% (n=13)	5.41% (n=10)	4.08% (n=41)
	Usual activity	34.26% (n=111)	23.81% (n=50)	26.48% (n=76)	14.59% (n=27)	26.24% (n=264)
	Pain	**44.14% (n=143)**	**30.48% (n=64)**	**49.13% (n=141)**	**41.08% (n=76)**	**42.15% (n=424)**
	Anxiety, Depres.	31.79% (n=103)	21.43% (n=45)	32.06% (n=92)	22.70% (n=42)	28.03% (n=282)
Problems	Mobility	0.00% (n=0)	0.00% (n=0)	0.35% (n=1)	0.00% (n=0)	0.10% (n=1)
	Self-care	0.31% (n=1)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.10% (n=1)
	Usual activity	**9.26% (n=30)**	1.90% (n=4)	2.09% (n=6)	3.78% (n=7)	4.67% (n=47)
	Pain	2.16% (n=7)	3.81% (n=8)	4.88% (n=14)	1.62% (n=3)	3.18% (n=32)
	Anxiety, Depres.	1.85% (n=6)	**5.71% (n=12)**	**7.32% (n=21)**	1.62% (n=3)	4.17% (n=42)

Nearly half of respondents (42.15%, n=424) complained about experiencing at least some pain. Table 5.36 explores the prevalence of pain. The pattern of pain experience mirrors the time on ART by period as seen in Table 5.29. This indicates that HCW should be vigilant in asking about patients' experience of pain even if the patient has been on ART for an extended period. Pain can be symptomatic of several side-effects (especially peripheral neuropathy) or OIs and can ultimately influence treatment adherence.

Table 5.36 Pain

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
No pain (in months)	0-3	8.33% (n=27)	8.57% (n=18)	8.71% (n=25)	8.11% (n=15)	8.45% (n=85)
	0-12	26.85% (n=87)	24.76% (n=52)	22.65% (n=65)	20.54% (n=38)	24.06% (n=242)
	13-24	17.59% (n=57)	16.67% (n=35)	9.76% (n=28)	9.73% (n=18)	13.72% (n=138)
	25-35	8.95% (n=29)	13.81% (n=29)	7.67% (n=22)	18.38% (n=34)	11.33% (n=114)
	37-48	0.31% (n=1)	10.48% (n=22)	5.92% (n=17)	8.65% (n=16)	5.57% (n=56)
	49+	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)
	All	53.70% (n=174)	65.71% (n=138)	45.99% (n=132)	57.30% (n=106)	54.67% (n=550)
Moderate pain (in months)	0-3	**7.10% (n=23)**	**7.14% (n=15)**	8.36% (n=24)	4.86% (n=9)	7.06% (n=71)
	0-12	**22.84% (n=74)**	**14.29% (n=30)**	**21.60% (n=62)**	**12.97% (n=24)**	**18.89% (n=190)**
	13-24	**13.27% (n=43)**	**6.67% (n=14)**	**9.41% (n=27)**	**12.43% (n=23)**	**10.64% (n=107)**
	25-35	6.48% (n=21)	6.19% (n=13)	**11.15% (n=32)**	**10.81% (n=20)**	**8.55% (n=86)**
	37-48	0.93% (n=3)	3.33% (n=7)	6.97% (n=20)	4.86% (n=9)	3.88% (n=39)
	49+	0.62% (n=2)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.20% (n=2)
	All	44.14% (n=143)	30.48% (n=64)	49.13% (n=141)	41.08 (n=76)	42.15% (n=424)
Extreme pain (in months)	0-3	0.62% (n=2)	1.43% (n=3)	0.70% (n=2)	0.00% (n=0)	0.70% (n=7)
	0-12	2.16% (n=7)	2.38% (n=5)	2.44% (n=7)	0.54% (n=1)	1.99% (n=20)
	13-24	0.00% (n=0)	0.48% (n=1)	0.70% (n=2)	0.54% (n=1)	0.40% (n=4)
	25-35	0.00% (n=0)	0.95% (n=2)	1.39% (n=4)	0.54% (n=1)	0.70% (n=7)
	37-48	0.00% (n=0)	0.00% (n=0)	0.35% (n=1)	0.00% (n=0)	0.10% (n=1)
	49+	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)
	All	2.16% (n=7)	3.81% (n=4)	4.88% (n=14)	1.62% (n=3)	3.18% (n=32)

Berg *et al* (2009: 244-247) describe an association between physical pain, depression and self-efficacy. Evidently depression and negative self-efficacy are strongly associated with psychological distress and poor adherence.

Respondents were asked to rate their overall QOL on a scale from zero to 100. Respondents seemed to report better QOL ratings as time on ART progressed, as shown in Table 5.37. All the cohorts indicated more than 50% of the respondents rated their QOL as above 50% (positive) at different time intervals.

Table 5.37 Self-rating of QOL

Indicator		0-25%	26-50%	51-75%	76-100%	Total
Time in months on ART	0-3	8.59% (n=14)	**32.52% (n=53)**	**30.06% (n=49)**	28.83% (n=47)	100.0% (n=163)
	0-12	6.19% (n=28)	**32.74% (n=148)**	**31.42% (n=142)**	29.65% (n=134)	100.0% (n=452)
	13-24	6.83% (n=17)	**34.94% (n=87)**	27.31% (n=68)	**30.92% (n=77)**	100.0% (n=249)
	25-35	3.38% (n=7)	26.09% (n=54)	**27.54% (n=57)**	**42.99% (n=89)**	100.0% (n=207)
	37-48	4.17% (n=4)	23.96% (n=23)	**27.08% (n=26)**	**44.79% (n=43)**	100.0% (n=96)

The 49+ month data are omitted due to the small sample

Mannheimer *et al* (2005: 18) found that QOL improves over time for HIV-infected individuals receiving ART. This study support the finding by Mannheimer, because fewer rated their QOL at more than 75% during the first three months, while nearly 50% rated their QOL more than 75% after three years on treatment. It seems as if there is a significant improvement in QOL up to two years on treatment; thereafter a plateau or slight improvement occurs. In another study improvements in QOL were noted as early as one month after initiation on ART for the physical, and four months after, for the mental dimensions of QOL. The improvements were most striking among those with the highest adherence levels (Sherr *et al*, 2008: 445, 446).

Respondents were questioned about hospitalization after ART initiation, as ART failure is significantly associated with increased self-reports of physical health complaints, and greater levels of psychological and cognitive complaints (Parsons *et al*, 2006: 5).

5.6.3. Hospitalization

One of the concerns of health systems is that the HIV-infected individuals are crowding out patients in hospitals (Tawfik and Kinoti, 2003: 22). With initiation of ART and the resulting restoration of the ART patient's immunity the need for hospitalization should diminish. Table 5.38 shows that a minority (16.80%, n=169) of the respondents have been admitted to hospital since ART initiation. The majority of them have only been admitted once (median one).

Table 5.38 Hospitalization

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Since initiation	Yes	15.74% (n=51)	10.48% (n=22)	19.51% (n=56)	21.62% (n=40)	16.80% (n=169)
	No	**84.26% (n=273)**	**89.52% (n=188)**	**80.49% (n=231)**	**78.38%(n=145)**	**83.20% (n=837)**
Number of admissions	Minimum	1.00	1.00	1.00	1.00	1.00
	Median	1.00	1.00	1.00	1.00	1.00
	Maximum	3.00	2.00	7.00	3.00	7.00

The conditions for which the respondents were hospitalized are recorded in Table 5.39. The overall condition was respiratory related (28.40%, n=48) which might be a further indication of PTB. Nearly a quarter (24.26%, n=41) of the respondents did not know the specific condition or did not want to elaborate and responses like "I felt ill" were given. Gastrointestinal complaints were prevalent (18.93%, n=32) and correlate with the experience of OIs respondents provided in Table 5.5. The data from Hope for Life was not meaningful as half (n=11) of the respondents did not provide a response to this question.

Table 5.39 Conditions resulting in hospitalization

Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Respiratory	**33.33% (n=17)**	0.00% (n=0)	**25.00% (n=14)**	**42.50% (n=17)**	28.40% (n=48)
Non-specific	**21.57% (n=11)**	4.55% (n=1)	**46.43% (n=26)**	7.50% (n=3)	24.26% (n=41)
Gastrointestinal	17.67% (n=9)	9.10% (n=2)	23.21% (n=13)	**20.00% (n=8)**	18.93% (n=32)
Neurology	9.80% (n=5)	4.55% (n=1)	8.93% (n=5)	15.00% (n=6)	10.06% (n=17)
Obs/Gyne/ Urology	7.84% (n=4)	**13.63% (n=3)**	12.5% (n=7)	2.50% (n=1)	8.88% (n=15)
Side-effects	13.73% (n=7)	4.55% (n=1)	3.57% (n=2)	5.00% (n=2)	7.10% (n=12)
Cardiology	1.96% (n=1)	0.00% (n=0)	10.71% (n=6)	5.00% (n=2)	5.33% (n=9)
Other	0.00% (n=0)	4.55% (n=1)	1.79% (n=1)	15.00% (n=6)	4.73% (n=8)
Dermatology	3.92% (n=2)	0.00% (n=0)	1.79% (n=1)	5.00% (n=2)	2.96% (n=5)
Hepatic	5.88% (n=3)	0.00% (n=0)	0.00% (n=0)	5.00% (n=2)	2.96% (n=5)
Endocrine	1.96% (n=1)	0.00% (n=0)	1.79% (n=1)	2.50% (n=1)	1.78% (n=3)
Cancer	1.96% (n=1)	4.55% (n=1)	1.79% (n=1)	0.00% (n=0)	1.78% (n=3)
Ophthalmology	0.00% (n=0)	4.55% (n=1)	1.79% (n=1)	2.50% (n=1)	1.78% (n=3)
Muscular-skeletal	3.92% (n=2)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	1.18% (n=2)

* Obs/Gyne/Urology = Obstetrics, Gynecology or Urology

5.7. Summary

Losina *et al* (2010: 1) declared that "maximal effectiveness of ART depends on timely HIV diagnosis, linkage to care, treatment initiation, and retention in care. The success of ART projects in South Africa depends in large part on the ability to identify HIV-infected individuals, to determine ART eligibility and monitor those not yet eligible for ART to facilitate timely transition to treatment, to initiate care among those eligible, and to ensure sustainable access to care over time". This underpins the importance of the continuum of care.

All the MOC provided ART in line with the SAG guidelines (South Africa, National Department of Health, 2003). Table 5.40 reflects some of the main findings on the continuum of care provided by the different projects.

Table 5.40 Continuum of care summarized

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
VCT only once ill	79.63%	71.90%	81.88%	63.78%
CD4 at baseline	118 [68:185]	116 [61:192]	121 [54:201]	124 [51:205]
ART naïve	95.06%	98.57%	94.08%	95.14%
Main regimen used	d4T-3TC-EFV	d4T-3TC-EFV	d4T-3TC-EFV	d4T-3TC-EFV
Regimen changed	8.02%	42.86%	10.10%	52.43%
Experienced side-effects	73.46%	65.71%	47.39%	55.68%
Main side-effect experienced	Rash 49.16%	PN 68.12%	Non-spec 38.97%	PN 32.04%
Complaint of pain	62.59%	48.94%	50.41%	32.43%
Disclosed status	97.84%	98.57%	90.59%	96.22%
Attended adherence training	83.02%	97.72%	95.12%	89.73%
Main trainer	Counselor 88.10%, R/N 10.41%	R/N 61.27%, Counselor 28.92%	Counselor 49.08%, R//N 46.52%	Counselor 89.16%, R/N 10.24%
Use Rx buddy	77.78%	76.19%	66.20%	81.62%
Attended support group	17.59%	53.33%	63.76%	63.78%
Home visits received	5.25%	78.10%	70.38%	49.19%
Missed visits	14.02%	10.48%	12.54%	9.73%
Main reason for missed visit	Transport 50.00%	No response 40.19%	Employment 25.00%	Away & forgot 33.33%
Complaint of pain	62.59%	48.94%	50.41%	32.43%
Site for accessing TB Δ & Rx	On-site, same hospital	On-site, SAG PHC clinic	Off-site, SAG PHC clinic	On-site, SAG PHC clinic
On ART & TB Rx	10.49%	4.29%	5.57%	5.95%
Ever on TB Rx	46.60%	37.14%	37.63%	40.00%
Ever on Cotrimoxazole	67.59%	96.67%	87.71%	83.78%

PN = peripheral neuropathy, Non-spec = Non-specific, Δ = diagnosis, Rx = treatment, R/N = registered nurse

It is apparent that entry into the projects is based on VCT done for ill individuals resulting in **late presentation for care**. At the time of the study patients were eligible to initiate ART at a CD4 count of 200 cells/mm^3 (South Africa, National Department of Health, 2004: 3)' yet the median baseline for respondents ranged from 116-124 cells/mm^3. The vast majority of respondents were treatment naïve and started on the then recommended **regimen** 1B (d4T-3TC-EFV). The fact that the respondents were largely treatment naïve is not surprising as ART only became available widely in South Africa after 2004 (Schneider *et al*, 2010: 1). It is, however, surprising that at all the projects the majority of the respondents were on the Efavirenz (EFV) based first-line regimen as Efavirenz can be teratogenic and is usually not the first-line choice for child bearing women (Wood and Martin, 2008: 279) . The respondents were mainly (70.58%) female with a median age of 37.5 years. The doctors at Hope for Life and Bela-Bela were very proactive in changing respondents' regimens (mainly to AZT-3TC-EFV) away from the Stavudine (d4T) containing regimen. The reason for changing the regimen might be peripheral neuropathy (main complaint at Hope for Life and Bela-Bela), which resulted in these respondents having fewer complaints of pain after the changes (complaints of pain less among Hope for Life and Bela-Bela respondents).

As disclosure is positively **linked with good adherence** (CAFOD, 2008: 8) it is encouraging to note that at all the projects more than 90% of the respondents disclosed their status. Another positive indicator is that the majority of respondents attended adherence training, although the levels are lower at Bela-Bela and St Apollinaris. Task-shifting of adherence training can be seen at St Apollinaris and Bela-Bela, with a lesser effect at Tapologo, where the training was done by counselors. Treatment buddies were deployed most at Bela-Bela and least at Tapologo, where the emphasis on treatment buddies is not as strong. Support groups were well utilized at Tapologo and Bela-Bela where nearly two thirds of the respondents attended support groups. At St

Apollinaris support groups were not well utilized and very few respondents received a home visit, demonstrating a lack of community-based support. The percentage of reported missed visits was also higher at St Apollinaris. Missed visits have been negatively correlated with adherence (Blacher *et al*, 2010: 1323; Watt *et al*, 2010: 381). The main resaon for missing visits at St Apollinaris were transport (indicating a problem to access care due to distance of travel), while respondents at Tapologo and Bela-Bela were not able to access services as they were working (Tapologo) or away (Bela-Bela) (indicating a problem with operating hours and mobile populations).

More respondents were on ART and TB treatment concurrently at St Apollinaris, the only project that provided TB and HIV treatment (Bela-Bela were very involved with the local PHC Clinic's TB program). The three NGO based projects had far fewer ART patients on TB treatment. The same pattern is seen in the percentage of respondents ever on TB treatment. St Apollinaris, however, provided less prophylaxis (Cotrimoxazole) to respondents.

The care provided at the different projects was delivered and influenced by the care providers available at each project. Chapter Six describes and discusses the care providers available at each project.

CHAPTER 6: CARE PROVIDERS

The World Health Organization (2006: xv, 12) classifies all people whose primary function is to enhance the health of others as HCWs. In 2006 they warned that there is a shortage of HCWs, in excess of four million, globally. Since then, and even before that, the shortage of staff has been credited with the failure to reach the 3 by 5 goals and identified as a threat to the accomplishment of universal access and the three health-related Millennium Development Goals (Barnighausen, Bloom and Humair, 2007: 800; Wadee and Khan, 2007: 142; World Health Organization, 2006: 19).

The HIV epidemic has worsened the burden of disease and placed a significant additional load on the health workforce. Furthermore, the HIV epidemic contributes to attrition of the workforce through illness and increased family responsibilities, making them unavailable to implement HIV interventions (McCoy, McPake and Mwapasa, 2008: 1, 2; National Department of Health, 2003: 102). Beck and Walensky, (2008: 55, 56) attribute the human resource problems associated with scale-up of HIV in low and middle-income countries to:

- ✓ Aging populations in high-income countries that increase the need for long-term care. These countries recruit from middle- and lower-income countries to fulfill their needs.
- ✓ Massive impact of HIV on an overwhelmed health system; people living with HIV (PLWHA) filling up more and more hospital beds.
- ✓ Low morale among HCW due to poor working conditions and lack of incentives to stay in the health sector.

Implementing an ART project within these constraints is challenging as ART projects are labor intensive (Steyn, Van Rensburg and Engelbrecht, 2006: 101) This chapter will focus on the HCWs utilized at the four MOC under discussion.

6.1. HCW shortage in South Africa

South Africa and its low- and middle-income counterparts in SSA are experiencing a dire shortage of key HCWs with only 0.77 doctors and 4.08 nurses per 1,000 persons in-country (Daviaud and Chopra, 2008: 46; Wadee and Khan, 2007: 142). The shortage is worse in some areas as the number of HCWs is not distributed equally throughout the country. Daviaud and Chopra (2008: 47) found that in some rural South African districts the overall number of doctors was only seven percent of the required number. It is in these very districts that the HIV prevalence is higher than the National prevalence rate (South Africa, 2010: 34).

Steyn, Van Rensburg and Engelbrecht (2006: 102-104) listed the factors affecting the availability of health professionals throughout South Africa as the:

- ✓ Unequal geographic distribution between provinces and rural and urban areas
- ✓ Unequal distribution between the private and public sectors with half of the HCWs tasked to provide care for more than 80% of the population
- ✓ High number of vacant posts in the public sector
- ✓ Insufficient production of nurses by training institutions
- ✓ Emigration of HCWs to other countries and
- ✓ HIV & AIDS epidemic

Human resource constraints are more challenging than other health system constraints. Drug supply, laboratory equipment or facilities can be obtained relatively quickly with sufficient funding; yet human resource shortages cannot be obtained in the short-term due to long education and training programs (Barnighausen, Bloom and Humair, 2007: 800). With the overall shortage in-country, recruitment from existing staff for ART projects might lead to weakening of the health system as HCWs flock to better paying HIV positions. An example of this internal brain drain was found in the Free State. Van Rensburg *et al* (2008: 7) found that more than 80% of the registered nurses recruited for the ART projects came from within the same province's public system, many from the same facility. The human resource crisis will deepen as the demand for HCWs increases and as the goal of universal access becomes more of a reality and people need lifelong treatment (Barnighausen, Bloom and Humair, 2007: 803).

The HIV epidemic not only affects the human resources that provide the ART, but also the location of treatment provision. The focus has been on hospital-based HIV projects. It is a fact that hospitals are not always accessible to all (Section 1 alluded to the transport problems respondents faced) due to the distances that need to be traveled to reach them. Hospitals also grapple with managing the increase in disease burden because of shrinking human resources (World Health Organization, 2006: 1) with the high number of HIV-positive patients crowding out other patients in need of care (Akintola, 2004: 2). Conventional care and support methods would not be possible in the face and extent of the HIV epidemic (Mahilal, 2006: 65). Traditional MOC for ART provision that focuses mainly on doctor-led care, based at a hospital, is therefore not sustainable if universal access is to be achieved and millions of people to be maintained on ART. There is thus a shift in the MOC from hospital-based care to HBC. The Committee on a National Strategy for AIDS (1986: 101) in the United States concluded that for patient care to be comprehensive and cost effective it must be conducted in the community as far as possible. This sentiment is supported in South Africa as both the *Comprehensive Plan* (South Africa, National Department of Health, 2003) and the *NSP 2007-2011* (South Africa, 2011) set universal access to HBC as one of their main goals (Schneider *et al*, 2010: 8). The next section will focus on the staffing levels at the different projects and the role different cadres of HCWs played and the setting in which the services were provided.

6.2. Staffing levels for ART delivery

With the onset of the ART program in 2004 the National DoH (South Africa, National Department of Health, 2003: 4) published the *Comprehensive Plan*. The *Comprehensive Plan* set out to develop staffing norms and standards for the delivery of ART. These standards included a list of the professional HCWs needed to treat patients with HIV, including health system managers, doctors, registered nurses, pharmacists, nutritionists and counselors. The staffing levels utilized at the projects compared to the staffing norms of the *Comprehensive Plan* (South Africa, National Department of Health, 2003) are reflected in Table 6.1. It is evident that the projects did not have dieticians available. Social workers were only available at St Apollinaris and Tapologo. Counselors were in short supply at all the projects but Bela-Bela.

Table 6.1 Staff levels in comparison with the standards set out in the *Comprehensive Plan*

	Standard **	**St Apollinaris**		**Hope for Life**		**Tapologo**		**Bela-Bela**	
Patient numbers	500	1,253		412		860		370	
Staff	#	Need	Actual	Need	Actual	Need	Actual	Need	Actual
Doctor(s)	1	2	1	1	2*	1	2*	1	2*
Registered nurses	2	5	3	2	2+5*	3	2 +8*	2	2*
Dietician	1	2	0	1	0	1	0	1	0
Social worker	1*	1	1	1*	0	1*	1	1*	0
Counselors	5	10	6	5	2	8	6	5	7
Data Capturers /clerk	2	5	4	2	1	3	3	2	0
Pharmacists	1	2	1*	Centralized					
Total	12.5	27	15.5	11.5	5.5	15.5	17	11.5	9

* Part-time staff, ** (South Africa, National Department of Health, 2003: 106)

Legend for Table 5.1 *At standard* *Lower than standard* *Higher than standard*

St Apollinaris (as a DoH managed hospital) followed the model suggested in the *Comprehensive Plan* (South Africa, National Department of Health, 2003) although the staff levels were not sufficient. Hope for Life followed suit with a serious shortage of non-medical staff like counselors and data capturers. The additional five registered nurses indicated were not funded by the ART project. They work at the HBC projects that refer patients to the centralized ART clinic. Tapologo has a large program that includes ART, HBC, PHC and an in-patient hospice. The ART project is funded separately from the other projects. They had the service of two part-time doctors. These doctors assisted on a sessional basis. Each of the ART delivery points was visited twice a month for two hours (32 hours a month in total). The rest of the clinical work is done by registered nurses. There seems to be an excess of doctors, registered nurses and data capturers, but it has to be highlighted that only two of the registered nurses are full time on the ART project and that the main focus of eight of the registered nurses' work is HBC. They assist the antiretroviral team once a week on certain days when the antiretroviral team visits the area. Bela-Bela was heavily dependent on two part-time doctors, with occasional sessions from an ophthalmologist, dermatologist, physician and gynecologist The rest of the cadres of workers were severely understaffed.

It is clear that the majority of the projects operated with fewer staff than the numbers recommended in the *Comprehensive Plan* (South Africa, National Department of Health, 2003). These findings are in line with those of other studies. Daviaud and Chopra (2008: 48) found an excess of registered nurses in some clinics, but described a shortage of other cadres of HCWs, cancelling out the benefit of the excess in many facilities.

At the onset of the *Comprehensive Plan* doctors, with special certification, situated at district hospitals were tasked with prescribing ART. Registered nurses, with special training, could assist patients within their PHC role. When available, dieticians and social workers were required to do direct patient counseling with lay counselors responsible for support work (South Africa, National

Department of Health, 2003: 108, 116). These standards were not realistic in some settings and could not be followed. One case in point was described in the Free State public treatment program where the standards for human resources were adapted based on local dynamics and resources to demonstrate the diversity of professionals needed to provide ART (Steyn, Van Rensburg and Engelbrecht, 2006: 100. 101). Other cadres of HCWs were therefore used. The same phenomenon can be seen in this study.

Table 6.2 reflects the additional staff available to assist in the ART project. At the NGO based projects (Hope for Life, Tapologo and Bela-Bela) there are no laboratory- or pharmacy-workers as these services are centralized (see section 4.5).

Table 6.2 Additional staff available

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Project/Unit Manager	1	1	1	1
Coordinator	1	1	1	0
Enrolled/ Auxiliary nurses	2	0	1	0
Administrator	0	0	1	0
HBC-workers	50*	35*	90*	26
Laboratory staff	4	Centralized		
Pharmacy assistant	8	Centralized		

* Part-time staff

These additional staff members can assist with supplementary tasks, making task-shifting possible.

6.3. Task-shifting

The World Health Organization (2006:24, 25) emphasizes task-shifting between HCWs as a solution to expand the clinical team. The non-professional team members need to be competent and supervised and need to have access to professional staff. This could be done by:

- ✓ Shifting tasks to the lowest relevant cadre
- ✓ Including PLWHA in the clinical team and
- ✓ Placing emphasis on patient self-management and community involvement

The shift is not only done between cadres, but also from a hospital-based to a community-based approach. This new emphasis on multidisciplinary and intersectoral approaches means changing roles for staff. These changes present a challenge for regulatory agencies as scope-of-practice regulations are meant to set minimum standards and protect patients (World Health Organization, 2006b: 26).

Task-shifting is not a new phenomenon and has been informally used before. However, the explosion of the HIV & AIDS epidemic, with the accompanying increased need for HCWs, has put new emphasis on task-shifting (Callaghan, Ford and Schneider, 2010: 1; Lehmann *et al*, 2009: 2).

Successful task-shifting requires a comprehensive and integrated reconfiguration of health teams with proper planning to avoid the risk of a fragmented and unsustainable approach (Lehmann *et al*, 2009: 2). Callaghan, Ford and Schneider (2010: 5) state that task-shifting has the potential to:

- ✓ Increase efficiency,

- ✓ Reduce the dependency on specialized doctors, thereby reducing cost, and
- ✓ Increase access to HIV services.

Nurse-managed ART was not found to be inferior to doctor-managed ART: in fact the follow-up of blood test was done more precisely and decentralized clinics (compared to hospital-based care) had fewer lost to follow-up patients with similar results in viral suppression, virological failure and mortality (Challaghan, Ford and Schneider, 2010: 5).

An example of task-shifting can be seen in Malawi (a country with a critical shortage of HCWs). There it enables registered nurses to diagnose and prescribe ART and lower cadres to dispense (McCoy, McPake and Mwapasa, 2008: 10). In South Africa task-shifting has been successful as well. Schneider, Van Rensburg and Coetzee (2007: 11) reported that universal access was achieved in two South African sub-districts by making use of existing professional staff through task-shifting. One of the most notable forms of task-shifting is the increased emphasis on registered nurse initiation and management of adult patients on ART. Table 6.3 shows that Tapologo is the only project where registered nurses initiated patients, while Bela-Bela was the only project where the registered nurses did not manage the patients on ART.

Table 6.3 Task division of staff

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Testing	n/a, parallel project	Counselor	Counselor	Counselor
Medical work-up	Registered nurse	Registered nurse	Registered nurse	Doctor
Adherence training	Counselors	Counselor	Counselor	Counselor
Initiation	Doctor	Doctor	Registered nurse	Doctor
Difficult cases	Doctor	Doctor	Doctor	Doctor
ART follow-up	Registered nurse	Registered nurse	Registered nurse	Doctor
HBC	HBC-worker	Registered nurse * HBC-worker	Registered nurse * HBC-worker	Registered nurse HBC-worker

* Nurses not from the ART clinic, these nurses supervise the HBC-workers

The information in Table 6.3 reflects the trends discussed in Table 6.1. St Apollinaris and Hope for Life followed a more traditional model that is doctor-dependent, with the support of registered nurses. Tapologo on the other hand was more nurse-dependent with the support of a doctor. Bela-Bela has a very doctor-dependent model with limited scope of practice for the registered nurse. The next section focuses on the role of the registered nurses in the projects.

6.3.1. The role of the registered nurse

At first the *Comprehensive Plan* (South Africa, National Department of Health, 2003) did not make provision for registered nurses to be involved in the initiation of ART delivery (Geyer, 2010: 15). This policy changed with the *NSP 2007 – 2011* (South Africa , 2007) which clearly indicated that the following objectives should be met by 2011 (South Africa , 2007: 78):

- ✓ 70% of adults must be started on ART in settings outside of hospitals,
- ✓ 80% of adults must be started on ART by registered nurses,
- ✓ 80% of adults on ART must be managed by registered nurses.

These set objectives clearly emphasize that registered nurses should form the core of the team providing ART in South Africa and that they have the potential to make a very large impact on the health of South Africans (Stender, 2010: 34; Van Rensburg *et al*, 2008: 7; Van Rensburg *et al*, 2008: 9; McCoy, McPake and Mwapasa, 2008: 220).

Only the Tapologo project followed this approach where registered nurses start adult patients on ART with limited support from the doctors.

Table 6.4 tabulates the roles of the registered nurse by project. It emphasizes the traditional roles fulfilled by the registered nurses at St Apollinaris and Hope for Life and the underutilization of the registered nurses at Bela-Bela. Tapologo worked towards the objectives listed in the *National Strategic Plan 2007-2011* above.

Table 6.4 The role of the registered nurse

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Responsibilities	- Admit patients to the ART clinic - Take blood from patients - Do patient consultations - Prescribe OI medication - Do counseling - Supervise other cadres of nurses - Provide patient health education - Order stock - Document care provided in patient's file	- Admit patients to the ART clinic - Take blood from patients - Do patient consultations - Prescribe OI medication - Do counseling - Supervise HBC-workers - Provide patient health education - Assist with grant applications - Order medication - Document care provided in patient's file	- Admit patients to the ART clinic - Take blood from patients - Do patient consultations - Initiate ART - Prescribe OI medication - Do counseling - Supervise and assist HBC-workers with Home visits - Provide patient health education - Do home visits - Document care provided in patient's file - Write nursing care plan for every patient	- Do home visits - Do adherence preparations - Translate for doctor
Involvement	Traditional role. Registered nurse works in support of the Doctor. Doctor initiated treatment.	Traditional role. Registered nurse works in support of the Doctor. Doctor initiated treatment. Registered nurse provides support to the HBC-workers at facility level	Nurse-led care, doctor supported model. Registered nurse initiate patients within the guidelines. Doctor assists with difficult cases. Registered nurses also provide community based care and supervise HBC-workers	Treatment predominantly done by doctor. Registered nurse provides support to HBC-workers and does community based care.

It's doubtful if these objectives in the National Strategic Plan 2007-2011 will be met. There are still several hurdles to overcome. The challenges are not only to train registered nurses to provide nurse-initiated and managed ART (NIM-ART), but also to have the supporting legislation promulgated (Geyer, 2010: 15).

Currently registered nurses are able to keep and supply medicines to their patients under the following circumstances:

- ✓ "In accordance with the provisions of the Medicines related Substance Act, 1965 (Act 101 of 1965) of the Pharmacy Act "*no nurse … may prescribe a medicine or Scheduled substance unless he or she has been authorized to do so by his or her professional council concerned*" (s22A(14)b).
- ✓ Keeping and supplying medicines to patients in hospitals or other institutions for the treatment of sick persons under direction of a

> medical practitioner and in accordance with the provisions of the Medicines and related Substances Control Act 101 of 1965" (South Africa, 1965: online).

However, the abovementioned provisions do not allow for registered nurses working in NGOs who may be guilty of a criminal offence and may be liable for disciplinary action if charged. Registered nurses working at Tapologo and Hope for Life have obtained dispensing licenses in accordance with the s22C of the Medicines and related Substances Control Act 101 of 1965" *"the Director-General may on application in the prescribed manner and on payment of the prescribed fee issue to a medical practitioner, … nurse … a license to compound and dispense medicines, on the prescribed conditions;…"* (s22C(1)a). (South Africa, 1965: online).

There might be concerns regarding nurse-led care. Humphreys *et al* (2010: 5) demonstrated that nurse-led care in a primary care setting was as good as, or better than, that in the hospital setting. Task-shifting is therefore an important tool to alleviate the shortages in healthcare. It may also enhance access to treatment by changing the setting where the treatment is provided. Thus community and home-based support could be vital.

Kabore *et al* (2010: 592) demonstrated the positive effect of combining clinical HIV & AIDS care (including ART) with the provision of community-based support services in four resource settings in SSA. A significant positive association between CD4 counts, overall QOL, ART adherence and community support were documented. HBC-workers can enable communities to reach their own people, within the boundaries of the communities' values and cultural norms, resulting directly in better health outcomes among patients. In a resource-poor area, with a shortage of HCWs, HBC-workers can play an important role in scaling-up ART by taking over a number of tasks from professional HCWs (Hermann *et al*, 2009: 1). Some of these tasks can be shifted to the community and form part of the HBC project. In this study all the projects provided ART at a "facility" as summarized in Table 4.1. However, a community can provide a multitude of support services to the patients on ART.

6.4. Home-based support

HBC is defined as care given to ill people in their homes within the community they live in. The goal of HBC is to provide hope through high-quality and appropriate care that helps sick people and families to maintain their independence and achieve the best possible QOL (World Health Organization, 2002a: 6). HBC can provide extended care and is not intended to be second best or cheap (South Africa, 2001: 2, 3). Cost effective studies showed that community-based care is considerably cheaper than hospital-based alternatives (Tawfik and Kinoti, 2003: 14; Russel and Schneider, 2000: 11, 12).

Patients should receive comprehensive care in the community and home. The care should subscribe to palliative care principles. Palliative care is the total active care of someone with an incurable illness, where the control of pain and other psychological, emotional and spiritual needs is addressed with the goal to improve the patient's QOL (Akintola, 2004: 13; Department of Health, 2001: 53) 53).

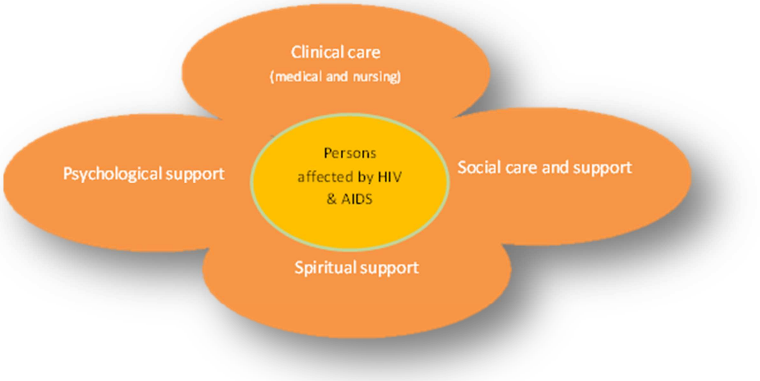


Figure 6.1 Comprehensive palliative care (Sebuyira, 2006: 15)

Figure 6.1 illustrates the components needed to provide comprehensive palliative support to PLWHA.

Clinical care includes treatment; pain and symptom management including OI treatment and prevention; nutritional support; adherence support (to ART) and end-of-life care. **Social care and support** strengthen affected households and communities with legal services, material and economic support including food security, clean water, etc. **Spiritual support** explores spiritual concerns including life review and assessment, counseling and life completion tasks. **Psychological support** includes counseling, emotional support, succession planning, treatment of psychiatric illness and stigma- and discrimination-reduction (Sebuyira, 2006: 15).

Apart from the already mentioned advantages, utilizing HBC can hold several other advantages. These advantages include the following:

- ✓ For PLWHA:
    - o Being comforted in their own surroundings
    - o Care is flexible and nurturing
    - o Activities can be undertaken as their symptoms are alleviated
    - o Family support for the sick can be secured with the help of HBC-workers
    - o Exposure to other infectious diseases in hospital settings is eliminated
    - o Increase of the possibility of adherence to complex drug regimens
- ✓ For the family:
    - o Caregivers can perform other duties apart from caring (time saved- no travelling needed to the hospital)
    - o Support systems can be accessed
    - o Training opportunities become available to families

    - Isolation experienced by families can be alleviated
    - Home care is cheaper for the family as no transport or time away from work is required
    - Promotion of awareness of HIV & AIDS, decreasing stigma and risky behavior
- ✓ For the community and volunteers:
    - Gain experience and become employable
    - Gain recognition from government organizations and the community
    - Gain a sense of meaning and respect
- ✓ For the health system:
    - Hospital and clinic admissions can decrease
    - The cost of hospitalization will be lower
    - Pressure on HCWs in facilities is relieved giving them the opportunity to assist others
    - Reduction of the burden on primary care systems as an result of health education about minor illnesses, nutrition and general wellness
    - Allowing for better monitoring between the health facility and the patient (Ogden, Esim and Grown, 2004: 26; Uys, 2003: 5; Russel and Schneider, 2000: 7)

The strong HBC component formed the backbone of the majority of the MOC. The four MOC under discussion provided HBC through different relationships with the other stakeholders.

St Appolinaris Hospital

At St Apollinaris the hospital formed a partnership with the local NGO, Izandla Zothando Centocow AIDS Project, providing HBC in the areas around the hospital. Izandla Zothando had 50 volunteers doing HBC. Prior to the data gathering visit the NGO lost its main source of funding and volunteers were no longer receiving any monetary support. The HBC group was under severe pressure due to the lack of resources. The HBC-workers were based in the community and had contact with the clinic through a HBC coordinator (a senior HBC-worker) not part of the team at the ART clinic, and did not have the support of a registered nurse. An enrolled nurse was employed to dispense supplies (Vaseline, Glycerin, cotton wool etc.) to the HBC-workers once a month. The enrolled nurse did not do supervisory or any other home visits.

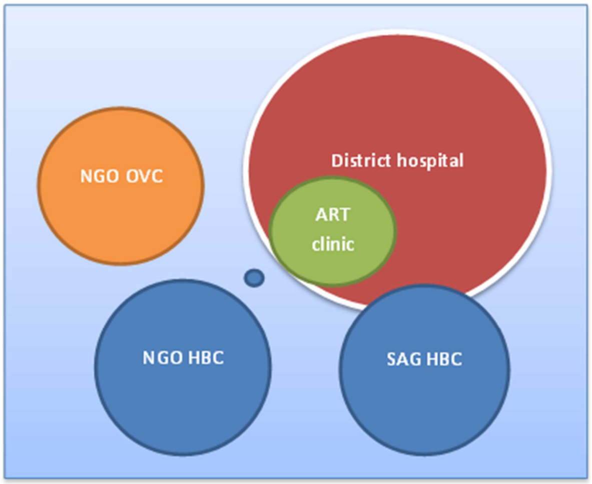


Figure 6.2 Relationships between stakeholders at St Apollinaris

The DoH did not fund the project and was partnering with another group of community-based care givers in the TB project. These community-based caregivers (SAG HBC in Figure 6.2) were responsible for TB activities (like DOTS and tracing of defaulters) and were paid a stipend. The relationship between the various elements working together is depicted in Figure 6.2.

Hope for Life

Hope for Life is part of an umbrella organization in the Winterveldt managed by the Sisters of Mercy. The HBC organization is part of a network of clinics, a hospice, feeding schemes, income generation projects, orphan care etc. The different groups within the network have a well-established referral system among each other. Figure 6.3 illustrates the close relationship between the NGO stakeholders and the SAG PHC Clinics at Hope for Life.

The HBC group (blue circle) comprise of 35 HBC-workers who receive a small stipend and belongs to one of eight HBC groups in the area. Patients are seen in the area where they live by a local HBC-worker. When needed, transport is arranged for the patient to attend the appropriate healthcare services. HBC services are thus decentralized with a centralized ART clinic. Registered nurses manage the HBC project well and supervise and train HBC-workers.

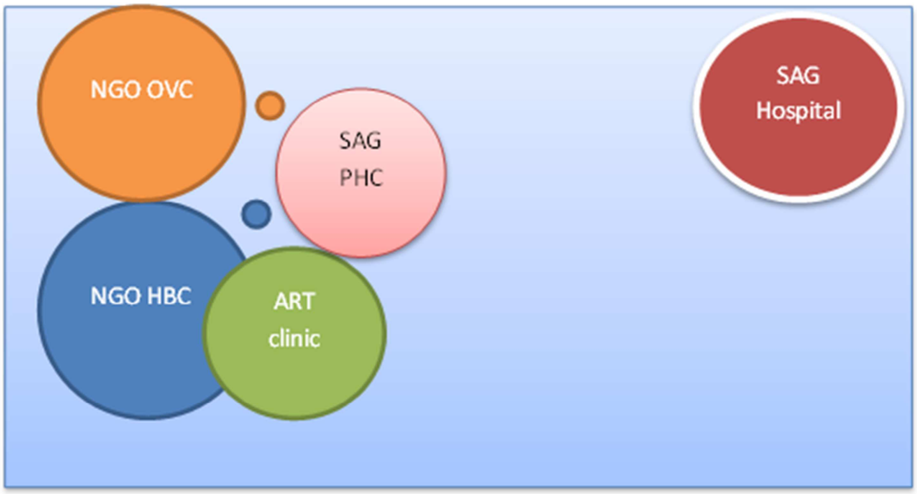


Figure 6.3 Relationships between stakeholders at Hope for Life

Tapologo

Tapologo is part of an umbrella organization assisting PLWHA in the Diocese of Rustenburg. In this network there are NGO-managed PHC clinics, Orphan projects, an in-patient Hospice, an ART project and a large HBC project. Figure 6.4 depicts the relationship between the stakeholders. Services were provided in nine areas. Each area had ten HBC-worker recruited from that area. Eight registered nurses worked and supervised the HBC-workers. ART services were brought to the patients via a mobile service model. The HBC and ART services were thus decentralized with a centralized management team and Hospice. HBC-workers and the HBC registered nurses were present at the ART clinic on the day the ART team visited the area. The HBC-workers also rotated through the IPU. The HBC-workers were thus involved in the full spectrum of care.

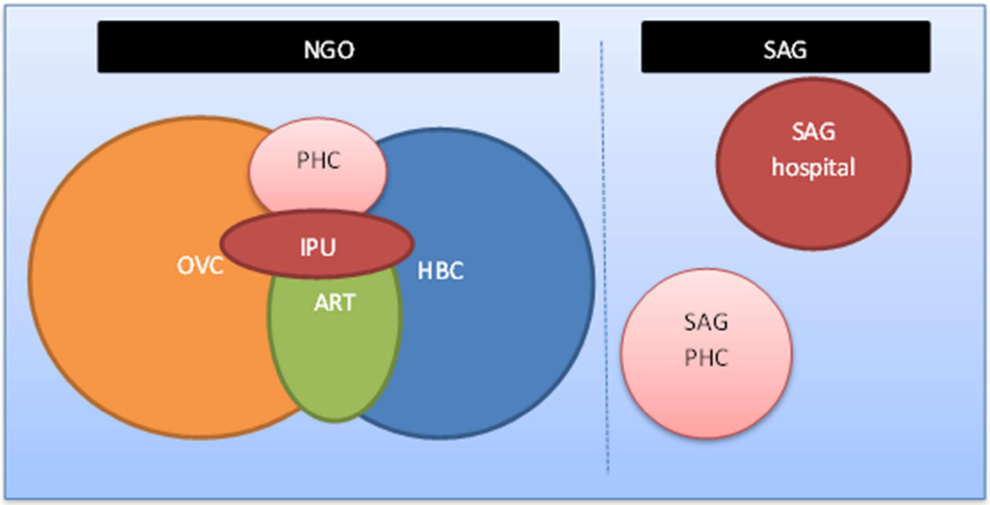


Figure 6.4 Relationships between stakeholders at Tapologo

Bela-Bela

Bela-Bela is a small NGO focused on HIV care and support. The project had 26 HBC-workers who worked at the three locations that were part of it. ART provision was centralized with decentralized community support. HBC-workers assisted at the ART clinic, ran support groups and did home visits. The HBC-workers used bicycles to reach their patients. A close relationship existed between the project and the DoH as shown in Figure 6.5. The project is based at the back of a SAG PHC clinic and employs two part-time registered nurses who do home visits as well. HBC-workers undergo extended training and are employed full-time by the project.

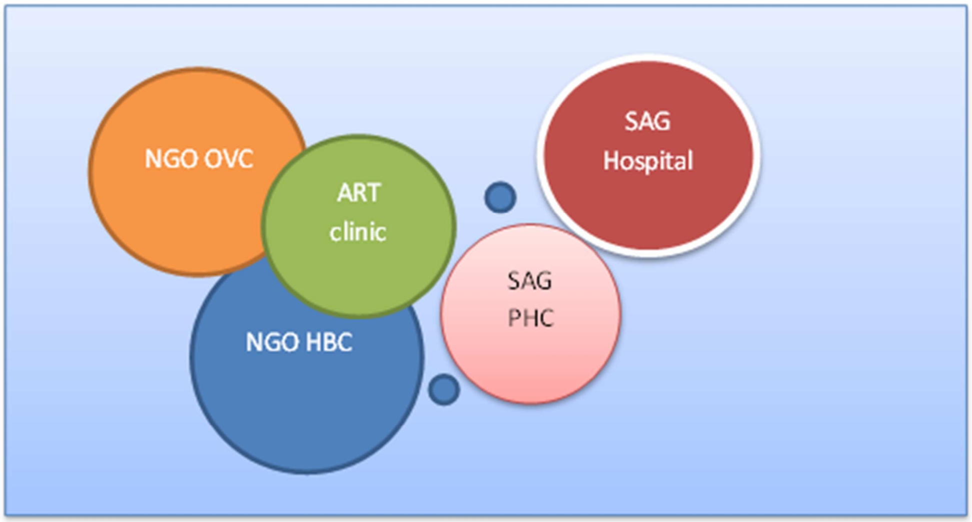


Figure 6.5 Relationships between stakeholders at Bela-Bela

The majority of the community-based care is provided in the patient's home during a home visit.

6.4.1. Home visits

Table 6.1 reflects the occurrence of home visits to respondents, the staff members who visited them and the frequency of these visits.

Table 6.5 Home visits received

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Received	Yes	5.25% (n=17)	78.10% (n=164)	70.38% (n=202)	49.19% (n=91)	47.12% (n=474)
	No	94.75% (n=307)	21.90% (n=46)	29.62% (n=85)	50.81%(n=94)	52.88% (n=532)
Mostly visited by	HBC	88.24% (n=15)	82.32% (n=135)	89.11% (n=180)	74.73%(n=68)	83.97% (n=398)
	Registered nurse	**0.00% (n=0)**	17.68% (n=29)	10.89% (n=22)	23.08%(n=21)	15.19% (n=72)
	Doctor	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	2.20%(n=2)	0.42% (n=2)
	Social worker	11.76% (n=2)	0.00% (n=0)	0.00% (n=0)	0.00% (n=0)	0.42% (n=2)
Frequency	Daily	0.00% (n=0)	2.63% (n=4)	7.54% (n=15)	7.87% (n=7)	5.69% (n=26)
	Weekly	35.29% (n=6)	35.53% (n=54)	45.23% (n=60)	50.56% (n=31)	42.67% (n=153)
	Monthly	47.06% (n=8)	35.53% (n=54)	30.15% (n=60)	34.83% (n=31)	33.48% (n=153)
	Other	17.65% (n=3)	26.32% (n=40)	17.09% (n=34)	6.74% (n=6)	18.16% (n=83)

The problems experienced at St Apollinaris with the HBC organization are noted in Table 6.5. Less than six percent (5.25%, n=17) of the ART patients interviewed were ever visited at home. The majority of visits were done by the HBC-workers (88.24%, n=15) and no visits were done by a registered nurse.

At Hope for Life (n=164) and Tapologo (n=202) more than 70% of the patients have received a home visit at least once. The majority of the visits was done by HBC-workers (83.97%, n=398) and a substantial number of patients at Hope for Life (17.68%, n=29) and Tapologo (10.89%, n=22) were visited by a registered nurse. At Bela-Bela nearly half (49.19%, n=91) of the patients have ever received a home visit at least once. The majority (74.73%, n=68) of visits were done by HBC-workers, although slightly fewer than at the other two projects. The registered nurse played a more important role here as she visited nearly a quarter (23.08%, n=21) of the patients.

The vast majority of patients who received home visits received a home visit weekly or monthly.

The respondents were asked about the nature of the assistance given during the home visit. It was clear that the vast majority of the visits revolved around adherence, economic and emotional support. Adherence support contained a vast array of activities aimed at reminding the patient to take ART. Economic support included the provision of food parcels or assistance to obtain food or social grants. Emotional support included counseling and psychological support. Table 6.6 tabulates the services provided by HBC-workers during visits, while Table 6.7 reflects the services provided by registered nurses.

Table 6.6 Services provided by HBC-workers during home visits

	St Apollinaris	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Adherence support	**17**	**169**	**225**	**109**	**520**
Economic support	0	**62**	**30**	**7**	**99**
Emotional support	0	**20**	**35**	5	60
Education	2	4	20	**8**	34
Provide supplies	**5**	10	11	1	27
Household chores	**3**	8	8	**7**	26
Family support	1	0	0	3	4
Physical care	0	1	0	1	2
Total # responses	**28**	**274**	**329**	**141**	**772**
# of Respondents	**15**	**135**	**180**	**68**	**398**

= number of

The number of responses and not the percentage reached were presented as respondents gave more than one response. HBC-workers were more inclined to provide economic support and registered nurses more inclined to provide emotional support after providing adherence support.

Table 6.7 Services provided by registered nurses during home visits

	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Adherence support	0	**40**	**32**	**34**	**106**
Emotional support	0	**9**	**6**	**7**	**22**
Economic support	0	**3**	0	0	3
Provide supplies	0	2	0	0	2
Total # responses	**0**	**54**	**38**	**41**	**133**
# of Respondents	**0**	**29**	**22**	**21**	**72**

At St Apollinaris two respondents reported that a social worker visited them, and that the social worker provided them with education and adherence support. Two Bela-Bela respondents reported that a doctor visited them; they reported that the doctor provided them with adherence support, family support and economic support.

With effective ART, HIV has been recognized as a chronic illness (Igumbor, 2009: 1). This would call for a chronic care model when planning care for patients on ART. In chronic health management it is important that individuals and families take responsibility for their own health (Hattingh, Dreyer and Roos, 2006: 246). Swendeman, Ingram and Rotheram-Borus (2009: 1323) and Bodenheimer *et al* (2002: 2472) call for a focus on the combination of education and self-management skills.Table 6.6 and Table 6.7 does not reflect a chronic care model with emphasis on education or family assistance.

In order to determine if the respondents felt a need for services other than what was provided they were asked during the interviews if there was anything else they needed done during home visits. Table 6.8 reflects the additional needs expressed.

Table 6.8 Additional services needed

	St Apollinaris	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Nothing else	**9**	**103**	**96**	**56**	**264**
Economic support	1	**20**	**38**	**8**	**67**
Adherence support	**2**	**21**	**26**	7	**56**
House chores	**2**	9	10	**8**	29
Emotional support	0	12	7	3	22
Family support	1	14	2	2	19
Physical care	0	1	2	0	3
Confidentiality	**2**	1	0	0	3
Education	0	0	2	0	2
Total	**17**	**181**	**183**	**84**	**465**
Respondents	**17**	**164**	**202**	**91**	**474**

The majority of patients (n=264) replied that they did not need anything else. There were some requesting more economic (n=67) and adherence support (n=56), home chores (n=29) and emotional support (n=22). The lack of emphasis on physical care (n=3) can be attributed to the fact that the patients had all been on treatment, with resulting improved conditions. Patients with mobility problems might not have been interviewed due to their inability to reach the clinic where the interviews were conducted.

The World Health Organization (2002a: 9) reiterated that the first requirement for care is to ensure the basic needs of shelter, food, safe water, sanitation, cooking utensils and clothing are met. Providing effective HBC is difficult in areas where these basic needs are not met. The over-emphasis on economic support might be explained by Abraham Maslow's theory on the hierarchy of needs. Figure 6.6 depicts the hierarchy of needs as described by Maslow.

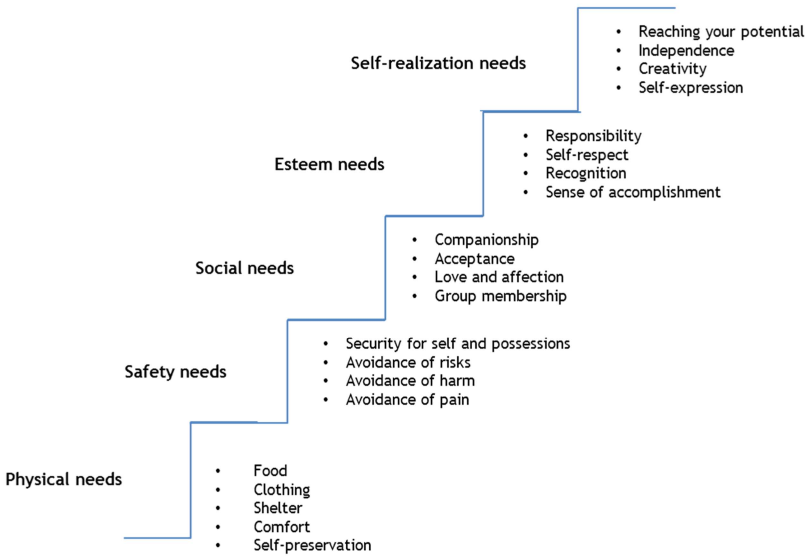


Figure 6.6 Abraham Maslow's Hierarchy of Needs (Herrington, 2010: online)

According to the hierarchy each individual's needs must be satisfied at the lower levels before they progress to the higher, more complex levels (Geyer, Mogotlane and Young, 2009: 203). As the level is met the person moves to the next level; all these needs are always present (Herrington, 2010: online). This might explain why respondents placed such a great emphasis on their immediate needs, not paying attention to self-management, future and succession planning (responsibility and independence).

Maslow's hierarchy of needs may be old, but according to Geyer, Mogotlane and Young (2009: 107) it remains useful for registered nurses as it facilitates an understanding of the relative importance of various human needs and it enables registered nurses to assign appropriate priorities to the needs of patients.

ART should have several positive impacts on HBC because it shifts the needs higher up in the hierarchy. As people start on treatment there is a good chance that they will recover their health and relieve the demand for care placed on the primary care giver. In addition the person receiving treatment may recover a healthy life for several years, during which he/she can help the household regain its stability. Through will-making and strengthening extended family ties arrangements can be made to ensure the family is looked after following the patient's death (Ogden, Esim and Grown, 2004: 33). However, ART does not avert the need for home care, it only changes the focus. This does not mean there should be no attention paid to palliative care.

ART is only a component of the continuum of palliative care (Sebuyira, 2006)(Sebuyira, 2006: 20; National Department of Health, 2003: 28). Even though the condition of the majority of the patients will improve during the use of ART palliative care could still provide the following:

- ✓ Pain and symptom control due to continuing conditions and side-effects
- ✓ Adherence follow-up through addressing social issues
- ✓ Supportive services like counseling, legal assistance, succession planning etc.
- ✓ Care for patients for whom ART has "failed"
- ✓ Care for those who have no access to ART (Sebuyira, 2006: 20).

A further concern regarding HIV projects is the tendency to provide HIV care as part of vertical systems.

6.5. Vertical care

The *Comprehensive Plan* stated clearly that the ART program was not intended to be a vertical program and that it had to be to be "*woven*" into the overall public health system (South Africa, National Department of Health, 2003: 103).

There is a clear trend in health reform towards integration and decentralization of services. Decentralization of services occurs where PLWHA can receive drugs and treatment in their local clinics and be cared for at home (Tawfik and Kinoti, 2003: 13). Integrated care (further discussed in Chapter Seven) at primary care level, however, requires HCWs at that level. Castelli *et al* (2010:29) list some of the challenges attracting HCWs at the primary care level:

- ✓ Most qualified HCWs in resource-settings are concentrated in urban areas
- ✓ Brain drain from resource poor settings to industrialized countries
- ✓ Training and qualifications in resource poor settings might be inadequate
- ✓ Vertical projects to manage HIV & AIDS receive funding more easily and lead to vertical systems for chronic healthcare.

All four of the projects evaluated in this study provide vertical care. St Apollinaris is the only project within a district hospital providing general health services, although the ART clinic (Ethembeni) is still separate from other services.

The patients were asked if they would prefer to receive ART services as a vertical (separate from other conditions) or an integrated care system (HIV services provided at the same location as services for other conditions). Table 6.9 tabulates the patients' responses. St Apollinaris patients had a near tie (51.58%, n=163 vs. 48.42%, n=153), where two-thirds of Hope for Life (66.03%, n=138) and Bela-Bela (61.62%, n=114) patients felt vertical care is preferable. At Tapologo nearly eighty percent (78.40%, n=225) of the patients preferred vertical care.

Table 6.9 Patients' choice of integrated or vertical care

Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Vertical	**51.58% (n=163)**	**66.03% (n=138)**	**78.40% (n=225)**	**61.62% (n=114)**	**64.19% (n=640)**
Integrated	48.42% (n=153)	33.97% (n=71)	21.60% (n=62)	38.38% (n=71)	35.81% (n=357)

Table 6.10 reflects the patients' reasons for choosing vertical care. The fear of HIV-negative patients and the fear of stigma dominated the patients' reasoning. Wilson and Fairall (2010: 514) also found that stigma seemed to be a problem in accessing HIV services, as people feared to be identified as positive when seeking care at a designated area within a facility.

Table 6.10 Patients' reason for choosing vertical care

Indicator	St Apollinaris (n=163)	Hope for Life (n=138)	Tapologo (n=225)	Bela-Bela (n=114)	All (n=640)
HIV-negative gossip	**39.26% (n=64)**	**24.64% (n=34)**	6.22% (n=14)	7.89% (n=9)	18.90% (n=121)
All patients are equal	14.11% (n=23)	6.52% (n=8)	**18.67% (n=42)**	**26.32% (n=30)**	16.09% (n=103)
Fear of being identified	6.13% (n=10)	**18.16% (n=25)**	2.22% (n=5)	0.00% (n=0)	6.41% (n=41)
Fear of stigma	0.00%(n=0)	6.52% (n=9)	4.89% (n=11)	**12.28% (n=14)**	5.31% (n=34)
Speedy service	10.43% (n=17)	2.90% (n=4)	0.89% (n=2)	6.14% (n=7)	4.69% (n=30)

The reasons for preferring integrated care are reflected in Table 6.11. The St Apollinaris respondents felt that integrated care might make the services more accessible and others would not be able to identify them as being HIV-positive. Stigma seems to be less of a factor at Bela-Bela, Hope for Life and Tapologo. Respondents explicitly said they do not fear stigma, that all patients are the same (HIV-positive or not) and that with integrated care they might have a chance to educate others about the disease.

Table 6.11 Patients' reason for choosing integrated care

Indicator	St Apollinaris (n=153)	Hope for Life (n=71)	Tapologo (n=62)	Bela-Bela (n=71)	All (n=357)
Do not fear stigma	1.32% (n=2)	**30.90% (n=22)**	**21.31% (n=13)**	**43.64% (n=31)**	**39.77% (n=68)**
All patients are the same	5.30% (n=8)	**11.27% (n=8)**	4.92% (n=3)	**11.30% (n=8)**	**15.79% (n=27)**
More accessible	**16.40% (n=25)**	1.41% (n=1)	0.00% (n=0)	0.00% (n=0)	7.28% (n=26)
Fear of being identified	**16.40% (n=25)**	0.00% (n=0)	0.00% (n=0)	1.41% (n=1)	7.28% (n=26)
Opportunity to educate others	5.30% (n=8)	5.63% (n=4)	**11.48% (n=7)**	**7.00% (n=5)**	6.72% (n=24)

Finally the respondents were asked how the services they received at the project under discussion compared to services received at other projects. Table 6.12 clearly reflects that the majority of respondents at St Apollinaris and Bela-Bela have not been exposed to alternative facilities and those who have been preferred the services at the named project. At Hope for Life the majority of respondents exposed to other facilities preferred the Hope for Life project, with a third of the patients never having been to another project. Half of the Tapologo respondents preferred the service provided at Tapologo while nearly half have not been to other facilities. These findings might be due to the fact that in the majority of these locations healthcare services are not available and the project providing ART might be one of the few healthcare facilities within reach of the respondents.

Table 6.12 Patients' opinion of the care received compared to that received in other health facilities in the area

Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Worse	0.93% (n=3)	0.00% (n=0) 0	0.70% (n=2)	0.54% (n=2)	0.60% (n=7)
The same	13.58% (n=44)	6.67% (n=14)	4.88% (n=14)	2.70% (n=5)	7.65% (n=77)
Better	25.31% (n=82)	**67.14% (n=141)**	**50.87% (n=146)**	38.92% (n=72)	43.84% (n=441)
n/a*	**60.19% (n=195)**	26.19% (n=55)	43.55% (n=125)	**57.84% (n=107)**	**47.91% (n=482)**

*n/a = not been to another project

A positive experience at a facility is important; Louis *et al* (2007: 490) reported that a poor experience at a facility can be associated with late presentation of care and will influence adherence and patient outcome. The respondents were asked about their experiences at the projects.

6.6. Quality of services rendered

The majority (96.22%) of the respondents felt comfortable and relaxed at the projects as seen in Table 6.13.

Table 6.13 Patients' perception of services received

Indicator		St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
Comfortable and relax	Yes	95.37% (n=309)	**99.05% (n=208)**	94.77% (n=272)	94.76% (n=179)	96.22% (n=968)
	No	4.63% (n=15)	0.95% (n=2)	5.23% (n=15)	3.24%(n=6)	3.78% (n=38)

The respondents were also requested to rate a list of ART-related services received at the project. The options were satisfied, neither satisfied nor dissatisfied, dissatisfied or do not know. The responses of respondents' who were satisfied are tabulated in Table 6.14.

In general the respondents reflected high levels of satisfaction with the care they received. The only two indicators that scored less than eighty percent were the complaint procedure and waiting time at St Apollinaris and Hope for Life. Schneider, Van Rensburg and Coetzee (2007: 19) reported that in a study done in the Free State the main complaint of patients was waiting times as well.

Table 6.14 Patients' rating of care received

Indicator	**St Apollinaris**	**Hope for Life**	**Tapologo**	**Bela-Bela**	**All**
Medical care	94.75% (n=307)	96.19% (n=202)	98.60% (n=282)	99.46% (n=184)	97.01% (n=975)
Complaint procedure	**69.75% (n=226)**	**64.29% (n=135)**	89.86% (n=257)	94.05% (n=174)	**78.81% (n=792)**
Cleanliness	95.68% (n=310)	99.05% (n=208)	87.76% (n=251)	98.92% (n=183)	94.73% (n=952)
Privacy	97.84% (n=317)	97.62% (n=205)	97.55% (n=279)	98.92% (n=183)	97.91% (n=984)
Confidentiality	93.83% (n=304)	99.05% (n=208)	98.60% (n=282)	100.0% (n=185)	97.41% (n=979)
Respect shown by nurses	97.53% (n=316)	99.52% (n=209)	99.30% (n=284)	98.38% (n=182)	98.61% (n=991)
Respect shown by doctor	99.07% (n=321)	97.14% (n=204)	98.60% (n=282)	100.0% (n=185)	98.71% (n=992)
Info provided on HIV	88.89% (n=288)	93.33% (n=196)	97.55% (n=279)	98.92% (n=183)	94.13% (n=946)
Info provided by nurses	91.05% (n=295)	95.24% (n=200)	97.55% (n=279)	97.84% (n=181)	95.02% (n=955)
Info provided by doctors	87.96% (n=285)	92.86% (n=195)	96.50% (n=276)	98.38% (n=182)	93.33% (n=938)
Ask questions	93.21% (n=302)	97.62% (n=205)	97.20% (n=278)	98.38% (n=182)	96.22% (n=967)
Language used	92.90% (n=301)	98.57% (n=207)	98.60% (n=282)	96.22% (n=178)	96.32% (n=968)
Hours open	89.51% (n=290)	85.71% (n=180)	92.66% (n=265)	92.97% (n=172)	90.25% (n=907)
Waiting time	**64.81% (n=210)**	**77.14% (n=162)**	84.97% (n=243)	87.03% (n=161)	**77.21% (n=776)**

Respondents were further asked how they would rate the care provided by HCW cadre. The majority of patients were satisfied with the care provided by professional HCWs. Less than eighty percent of the patients at St Apollinaris and Tapologo were satisfied with some of the support staff (administrative clerk and attendant staff e.g. cleaners). Table 6.15 tabulates the ratings of different healthcare cadres.

Table 6.15 Patients' perception of care provided by HCW cadre

Indicator	**St Apollinaris**		**Hope for Life**		**Tapologo**		**Bela-Bela**		**All**	
	√	x	√	x	√	x	√	x	√	x
Nurse	**93.83% (n=304)**	0.00% (n=0)	**96.67% (n=203)**	0.00% (n=0)	**97.56% (n=280)**	0.00% (n=0)	**97.30% (n=180)**	1.62% (n=3)	**96.12% (n=967)**	0.00% (n=0)
Doctor	**93.52% (n=303)**	0.31% (n=1)	**93.33% (n=196)**	1.43% (n=3)	**96.86% (n=278)**	0.70% (n=2)	**98.38% (n=182)**	0.00% (n=0)	**95.33% (n=959)**	0.60% (n=6)
Counselor	**90.43% (n=293)**	0.00% (n=0)	**91.90% (n=193)**	0.95% (n=2)	**97.21% (n=279)**	0.70% (n=2)	**98.92% (n=183)**	0.54% (n=1)	**94.23% (n=948)**	0.50% (n=5)
Clerk	**78.09% (n=253)**	1.23% (n=4)	**87.62% (n=184)**	0.48% (n=1)	**96.17% (n=276)**	0.35% (n=1)	**98.38% (n=182)**	0.54% (n=1)	**88.97% (n=895)**	0.70% (n=7)
Attendant staff	**76.54% (n=248)**	1.54% (n=5)	**89.05% (n=187)**	0.48% (n=1)	**79.08% (n=223)**	3.19% (n=9)	**94.05% (n=174)**	1.08% (n=2)	**83.12% (n=832)**	1.70% (n=17)

√ = satisfied, X = dissatisfied

The HCWs (providers) were also asked about their experiences working at the projects. Work satisfaction of health staff is important as it affects individual and organizational health outcome (Pillay, 2009: 1). Provider-patient relationships can also influence patient adherence to treatment (Gusdal *et al*, 2009: 1384; Ubbiali *et al*, 2008: 571). Negative staff attitudes can lead to poor adherence (South Africa, National Department of Health, 2010: 17).

6.7. Care providers' experience

Li *et al* (2007: 759) reported that staff with higher levels of institutional support provided better care to PLWHA and were less likely to discriminate against their patients. According to Pillay (2009: 3) HCWs in South Africa were mainly dissatisfied with remuneration packages, their career development opportunities and the resources available to them and the safety of their work environment. The HCWs experience will be discussed based on the setting (facility-based and community-based) they work in.

6.7.1. Facility-based HCWs

The staffs' (nurses and counselors) responses regarding their frustrations and challenges are tabulated in Table 6.16.

Table 6.16 Staff experiences

	St Apollinaris	***Hope for Life***	***Tapologo***	***Bela-Bela***
Patient related	- Very sick patients - Patients very poor, food insecurity - Patients who default - Pediatric patients (caregiver problems) - Unemployment rates high in area - Cultural influences on patients (women not adhering, men not involved/ do not give consent for wife to be on treatment)	- Patients very poor, food insecurity - Adolescent care difficult - Patients on treatment for a long time default when better	- Very sick patients - Patients very poor, food insecurity - Migrant population - No water in the area - Patient default due to grant n- i.e. Some patients choose grant over treatment	- Long-term side effects worrying - TB is a big problem - Language barriers
Facility related	- Clinic not open on a weekend - Problems with hospital pharmacy - Space in clinic limited	- Space in clinic limited, pending reallocation	- Hospice sometimes full - Space and infrastructure in clinic limited - Facility still far (7km) from patients - Staff travel far to facility - Crime in area of clinic	- Space in clinic limited
HR related	- Occupational compensation - Shortage of staff - Lack of support from top management	- Very high work load	- HBC-workers limited hours - Not all the nurses are committed	- Very high work load

Some of the complaints cut across different projects; patients being very sick, poor and food insecure or defaulting treatment. Space was a universal complaint regarding facilities. HCWs at Hope for Life and Bela-Bela complained about workload while St Apollinaris HCWs were the only group complaining about compensation and a lack of support from top management.

Registered nurses in the Free State public sector ART program also complained about considerable emotional and psychological distress (Steyn, Van Rensburg and Engelbrecht, 2006: 123). However, in other studies registered nurses reported that their ability to provide treatment and therefore hope, impacted positively on their general attitude towards work because it motivated staff to come to work every day and compensated for high levels of work-related stress (George *et al*, 2010: 79-81).

6.7.2. Community-based HCWs

HBC-workers participated in nominal groups conducted at the different facilities (see section 3.3.4). Data generated from twelve nominal groups (2 groups at St Apollinaris, 2 groups at Hope for Life, 5 groups at Tapologo and 3 groups at Bela-Bela) were reduced to eleven themes during thematic data analysis. The HBC-worker was asked "What do you need to be a good HBC-worker?" Table 6.17 reflects the outcome of these nominal groups.

Table 6.17 Themes ranked after voting

Ranked	St Apollinaris	Hope for Life	Tapologo	Bela-Bela	All
1	Remuneration	Continuum of Care	Support Networks	Continuum of Care	Support Networks
2	Support Networks	Support Networks	Aptitude	Patient-provider relationship	Aptitude
3	Skill building	Skill building	Remuneration	Aptitude	Continuum of Care
4	Poverty	Logistics	Continuum of Care	Teamwork	Remuneration
5	Supplies	Remuneration	Logistics	Support Networks	Skill building
6	Aptitude	Teamwork	Skill building	Poverty	Poverty
7	Patient-provider relationship	Supplies	Stakeholders	Logistics	Teamwork
8	Continuum of Care	Poverty	Poverty	Supplies	Logistics
9	Logistics	Aptitude	Teamwork	Remuneration	Supplies
10		Patient-provider relationship			Patient-provider relationship
11					Stakeholders

The needs identified by the HBC-workers include: support networks, aptitude, continuum of care, remuneration, skill building, poverty alleviation, teamwork, logistics, supplies, good patient-provider relationships and stakeholders. In line with NGT literature only the top five priorities will be discussed in the sequence of importance (Van Breda, 2005: 5; University of Illinois, n.d.). The first theme is support networks.

Support Networks

HBC-workers come from the same poverty stricken areas as their patients. In many instances they themselves, or close family members, are infected with HIV. Often they have to deal with stigma and discrimination, the emotional stress of repeated loss and the physical strain of walking long distances (Cameron, Coetzee and Ngidi, 2009:105; Dullaert, 2006: 1; Akintola, 2004: 23). Therefore, HBC-workers have similar emotional and psychological as well as socio-economic needs as the sick people they care for. Due to this they are at a high risk of being overwhelmed by the problems they encounter and at further risk for burn-out (Dullaert, 2006: III). It is therefore essential that the HBC-workers have a support network providing “care for the carer” (Akintola, 2004: 23, 42).

“Care of the carer” can consist of many interventions to reduce the vulnerability and exposure for people facing burn-out (Dullaert, 2006: 9). When burn-out occurs, people become despondent and lose their capacity to give compassionate care (Defilippi, 2003: 28). Supportive interventions may include training so that HBC-workers feel more confident. Reasonable payment will reduce financial burdens. Sufficient leisure time, debriefing and teambuilding sessions will reduce stress and promote compassionate care (Cameron, Coetzee and Ngidi, 2009: 105).

The HBC-workers at the different projects felt that they received support from a network of people.

The participants described the different support networks as:

- ✓ Patients: who love and respect them. Knowing they are making a difference.
- ✓ Community: The community refers patients to them and assists them. They feel the community appreciates them.
- ✓ Family: Their own family members provide support.
- ✓ Fellow HBC-workers: The HBC-workers are like a family and support each other.
- ✓ Church: Spiritual support and prayer as part of the project.
- ✓ The ART project: Monthly meetings, retreats and debriefing sessions.

> "We volunteer (no pay), but we are there for others. There is cooperation between the patients, the community and the HBC-workers. Communication with patients and their families is good."

Providing ongoing support is important in these FBOs. Another intervention is doing occasional retreats. Sr Alison Munro (2007: 83), explains: "Many people in Church projects have availed themselves of opportunities for a pastoral or spiritual retreat for HBC-workers, a time out to be quiet, a time where stories can be safely told, a time for prayer and reflection and to build relationships among HBC-workers".

In a study by Hlophe (2006: 203) HBC-workers in the Free State did not experience the network of support as positive. HBC-workers reported that some families shifted their responsibilities of care onto the HBC-workers, refusing to assist the patients, because the HBC-workers got paid to do it. Although the HBC's felt that communities, in general, have a positive attitude towards HBC-workers and their work, they were of the opinion that registered nurses and family members did not appreciate their work (Hlophe, 2006: 201-204). The second theme is aptitude.

Aptitude

The HBC-workers taking part in the nominal groups felt strongly that not just anyone could be a good HBC-worker. Aptitude is having the capability, ability, talent, innate or acquired capacity for something (Dictionary.com, 2011). The HBC-workers were very proud that they had the aptitude to be good HBC-workers:

The abilities they felt they had were:

- ✓ Love: A HBC-worker must have love in her heart for the patients and her work.
- ✓ Personal conduct: A HBC-worker needs to be professional, respect others, herself and God.
- ✓ Self-motivating: The HBC-worker must be self-motivated and determined to do a good job.

> "You must have compassion. Care for the family too. Love your job and the sick".

Some additional traits to consider when selecting HBC-workers could include:

- ✓ Using individuals living with HIV & AIDS for their experience of the situation (Hermann *et al*, 2009: 1, 2, 5).
- ✓ Taking into consideration the individual's emotional coping skills, previous stressful life experiences and current lifestyle which can equip the HBC-worker with additional strength. However, unresolved previous losses and present stressors heighten the probability for burn-out (Defilippi, 2003: 29).
- ✓ The individual's motivation to serve the community they will be based in (Hermann *et al*, 2009: 3).

Although HBC's may have the aptitude to care for an individual they should also be able to care for a patient at any point along the continuum of care from the acute phase up to the end stage of life.

Continuum of Care

In an era of ART, HIV & AIDS has moved from a fatal condition to a chronic but disabling illness. Long-term care remains vital. The ideal setting for patients would include a continuum of care that allows them to live in the community as long as possible (Ettner *et al*, 2008: 1177).

Continuum of care includes two key aspects (Russel and Schneider, 2000: 8), the range of services and the network of providers. The **range of services** provided to a person from the time of diagnosis to the time of death, including the impact on survivors (Mahilal, 2006: 68). The care provided by HBC-workers was tabulated in Table 6.6. This included clinical care, social care and support, spiritual support and psychological support. Comprehensive care involves the provision of care, treatment, support and preventative services (World Health Organization, 2002a: 46). The **network of providers** who care for the individual during this time work together to provide for the different needs that arise. Within a continuum of care, care is provided by a network of resources and services that provide holistic and comprehensive support to the patients and their family caregivers. The goal is to provide an affordable range of services in various settings, from home to community agencies, clinics to hospitals and vice versa. Holistic care involves referral, follow-up, monitoring and case management (World Health Organization, 2002a: 46).

HBC-workers are proud of the care they provide to the patients. The range of services provided in the continuum of care was described to include:

- ✓ Assisting with house chores like cleaning and cooking.

- ✓ Education, counseling and motivation of patients and family members.
- ✓ Adherence assistance including pill counts, education and motivation.
- ✓ Palliative care, including assisting patients to die with dignity.
- ✓ Bathing of patients and dressing wounds.
- ✓ Assisting at the clinic and in-patient hospice.
- ✓ Door-to-door campaigns.
- ✓ Community members refer to the HBC-workers.
- ✓ Referral of patients to the NGO and other public clinics.
- ✓ Referral to in-patient hospice for admission of the very sick.

> “At the hospice the ill patients get better.
> Others we help to die with dignity”

A small group of HBC-workers mentioned that the community did not want them to visit the sick. They expressed that they felt that high levels of stigma present in the communities could have contributed to this.

In section 6.4.1 it was noted that very little physical care education and family support were reported by respondents. During the nominal groups the HBC-workers confirmed that these services were provided. It confirms the notion that the patients who received these services recently might still be very sick and were unable to reach the clinic and were not included in the research sample.

Remuneration was the fourth theme and is surprisingly not higher on the priority list because many HBC-workers use their own money to provide for their patients.

Remunerationn

The HBC-workers asked for stipends, some for higher stipends. There was a clear sense of the HBC-workers having a need to be acknowledged for the work they do by receiving a monetary reward.

> "We use our own money to help the patients. We need money for thank you. Other volunteers get paid and look down on us."

The HBC-workers at St Apollinaris do not receive any monetary reward. The HBC-workers at Hope for Life and Tapologo received stipends, while Bela-Bela's HBC-workers were receiving salaries.

Some projects do not pay salaries to their HBC-workers due to a valid concern regarding the ongoing sustainability of projects and therefore prioritize the use of volunteers as a cost-saving measure (Hermann *et al*, 2009: 3, 4, 9; Uys, 2003: 12). In other cases donors are unwilling to fund stipends (Akintola, 2004: 38). It remains a contentious issue to expect individuals from impoverished communities to volunteer, thus creating an ethical and economic dilemma (Cameron, Coetzee and Ngidi, 2009: 103; Uys, 2003: 12).

Other projects pay the trained HBC-workers as part of the HBC team. In some projects volunteers are recruited from within the community and have some training, but they are not paid. Honoring these valued community volunteers is important. Some form of incentive (such as honorarium, in-kind payment and uniform, badges or T-shirts) is necessary (World Health Organization, 2002a: 62). True volunteers can also not be expected to work full-time and should only be asked to work a couple of hours a week (Hermann *et al*, 2009: 3, 4, 9).

Akintola (2004: 38) and Hermann *et al* (2009: 1) reported that evidence from HBC projects that make use of volunteers usually shows high rates of attrition.

Although individuals volunteer they do so with the hope of it leading to employment in the future (Mahilal, 2006: 79-81; Uys, 2003: 12). HBC-workers also volunteer for religious reasons. They might have previous experience of community work or they might be personally affected by HIV (Mahilal, 2006: 79-81). All volunteers are, however, poor and have to feed their families and could not be faulted for taking another opportunity for employment if it arises (World Health Organization, 2002a: 65).

These HBC projects invest a large portion of their budget to train volunteers. Uys (2003: 12) debates that the cost incurred to retrain volunteers due to attrition should rather be used to reward and thus maintain the volunteers.

Sr Alison Munro (2007: 93) confirms that in the Church's program "training and building-up capacity are never-completed tasks as training needs have to be met over and over again as new arrivals replace trained people who leave".

The issue of remuneration is, however, a difficult dilemma in the presence of a high burden of disease and competing priorities for scarce funding. The amount HBC-workers should be paid is contented. The majority of Government funded HBC-workers in the Free State received R500. Hlophe (2006: 208) found that a group of HBC-workers receiving a R500 stipend from the DoH felt that the money was too little for the work they did. They were cognizant that they were volunteers, but felt that they were not empowered to perform their tasks. In addition to more money they were also of the opinion that they should be better trained to perform their tasks.

Skill building

HBC-workers mentioned the need for workshops and training for HBC-workers:

"We need information to learn more"

HBC-workers are often expected to care for patients needing specialized care. When ill people are discharged early from a hospital to a HBC project they deserve the same quality of care that should have been offered at the hospitals by professionals (Uys, 2003: 12; Russel and Schneider, 2000: 9). ART adherence and management can also be complex. The HBC-workers thus need adequate training to be able to cope with the continually evolving needs of the patients and their family (World Health Organization, 2002a: 9). Furthermore, HBC-workers are expected to educate the family members and equip them with the skills relating to care and support for the ill person (Hlophe, 2006: 200). Training HBC-workers is essential if they are expected to provide good, quality care (Mahilal, 2006: 87).

Mahilal (2006: 87) found that most HBC organizations provide training. The modules and length of training vary, but the majority of the trainings focus on basic nursing skills, and emphasize the practical care of patients in the home. HBC-workers in general might thus not be sufficiently equipped to educate and train patients and family members in prevention, treatment and long-term self-management (World Health Organization, 2002a: 54).

HBC-workers in the Free State also believed that they have insufficient training and lack the knowledge and skills to perform their duties (Hlophe, 2006: 201).

If HBC-workers have to form part of the healthcare team and if task-shifting (discussed in section 6.3) is going to be successful, HBC-workers will need ongoing training (Hermann *et al*, 2009: 2).

Apart from the difference in monetary remuneration another noticeable difference was the role registered nurses played in the supervision of the HBC-workers. HBC-workers assisting the ART team at St Apollinaris were not supervised by a registered nurse. Registered nurses were available for supervision and assistance of the HBC-workers at the other three projects. The

Tapologo model had the best example of structured and well managed supervision. Each HBC-project was designed around a community-based registered nurse who supervised ten HBC-workers. The registered nurses were responsible for creating nursing-care plans for each patient and assisted HBC-workers were exposed to a variety of experiences because they worked in the community, ART clinics and hospice. At Hope for Life and Bela-Bela the registered nurse assisted with home visits, but the patient management was not nurse-led.

In South Africa HBC provides a backup system for patients discharged early from hospital or patients on ART; these patients often need extended care as discussed earlier (Hlophe, 2006: 195). Cameron, Coetzee and Ngidi (2009: 102) declared the supervision of trained non-professional caregivers by registered nurses as vital. HBC-workers should not be expected to work independently without the supervision and guidance of a registered nurse. In a team the registered nurse and the HBC-workers can provide holistic care together and increase the quality of care provided (Hermann *et al*, 2009: 1). The HBC-workers would also be sufficiently mentored to prevent burn-out (Uys, 2003: 13).

6.8. Summary

In order to scale up treatment and care, MOC need to take into consideration human resource constraints in resource-poor settings (Calmy *et al*, 2004: 2354; World Health Organization, 2007: 13, 14). Great focus was placed on the providers of care at the different MOC.

St Apollinaris was a traditional public facility with a project driven by the doctor and supported by the registered nurses. Counselors were mostly tasked with providing adherence counseling. Community-based care was very poor with only 5.25% of the respondents reporting ever receiving home visits.

Hope for Life followed a traditional clinic model that is doctor-driven and nurse-supported with less task-shifting visible. Doctors fulfilled traditional tasks such as initiating ART. Registered nurses were providing ART follow-ups and took responsibility for a substantial portion of adherence training. Community-based support was good with 78.10% respondents reporting ever having a home visit.

Tapologo followed a nurse-driven approach with support from doctors. ART and HIV care was provided in the communities through a decentralized community-based project. Task-shifting was done successfully with counselors taking responsibility for adherence training.

Bela-Bela followed a very heavy doctor-driven model. The registered nurses were not present in the clinic and were only responsible for community-based support together with the counselors. Nearly half (49.19%) of the respondents reported ever having a home visit. These care providers' roles are summarized in Table 6.18 and were discussed in-depth in this chapter.

Table 6.18 Care providers' roles at the different projects

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Model	Doctor-driven, Nurse-supported	Doctor-driven, Nurse-supported	Nurse-driven, Doctor-supported	Doctor-driven,
Setting for ART provision	Facility (hospital)	Facility (Clinic)	Outreach (community)	Facility (clinic)
Main trainer	Counselor	Registered nurse	Counselor	Counselor
ART initiation	Doctor	Doctor	Registered nurse	Doctor
ART follow-up	Registered nurse	Registered nurse	Registered nurse	Doctor
Difficult ART cases	Doctor	Doctor	Doctor	Doctor
Home visits received	5.25%	78.10%	70.38%	49.19%
Main visitor	HBC	HBC	HBC	HBC
Main reason for visit	Adherence support	Adherence support	Adherence support	Adherence support
Choose vertical care	51.58%	66.03%	78.40%	61.62%
Main reason for choice	HIV-negative gossip	HIV-negative gossip	All patient equal	All patients equal
Comfortable at project	95.37%	99.05%	94.77%	94.76%
Topics <70% satisfied	Complaint procedure Waiting times	Complaint procedure Waiting times	n/a	n/a
Main theme from HBC	Remuneration	Continuum of care	Support networks	Continuum of care
HBC nurse supervised	No	Yes	Yes	Yes
HBC stipend	No	Yes	Yes	Salary

All four of the MOC provided vertical care to their patients in a stand-alone ART Clinic. Even though at St Apollinaris the ART Clinic was part of a district hospital and the other projects offered other services in the communities they served, the ART provision points were only providing ART. More than half of the respondents at all the projects preferred vertical care as they felt that the HIV-negative patients (if ART would be integrated into PHC) would gossip about them. Although they felt that they were equal to HIV-negative patients, they preferred to have “a place of their own”.

Overall patient satisfaction was very high at all the MOC. When given a list of topics to rate patient satisfaction all the topics but complaint procedures and waiting times at St Apollinaris and Hope for Life scored more than 70%.

Strong community-based support was available at Hope for Life, Tapologo and Bela-Bela (NGO-managed models). At all the MOC the main reasons for home visits were adherence support, with a noticeable lack of focus on HIV as a chronic condition. When asked what was the most important aspect you need to provide good HBC, HBC-workers at Hope for Life and Bela-Bela replied that the continuum of care is vital, while HBC-workers at Tapologo valued the support networks available to them. HBC-workers at St Apollinaris felt that remuneration was the most important as they were not receiving any stipends. Community-based support at St Apollinaris was poor at the time. HBC-workers at the three NGO-managed MOC received remuneration and were supervised by a registered nurse; HBC-workers at St Apollinaris were not supported.

The final chapter will focus on the researcher’s recommendations regarding future HIV Care in South Africa, based on the findings of this study and supported by current literature.

PART III

The previous part of this document reflects the data generated during the study of MOC with relevant literature quoted as part of the text. The study is concluded in Part III, where the researcher focused on the changing demands of HIV care. Recommendations, based on the data and Chronic Care Model by (Wagner et al, 2002), are made to change the HIV healthcare delivery system in South Africa.

CHAPTER 7: The four MOC in retrospect and the needs for paradigm shifts

HIV remains a death sentence in the absence of access to ART (Paredes, Sherer and Clotet, 2008: 422; Beck and Walensky, 2008: 56). In SSA (the region most severely affected by the epidemic), 63% of HIV-positive individuals, eligible for ART, did not have access to the lifesaving treatment by 2010 (AVERT, n.d.: 2). Access to treatment will have to be scaled up significantly in order to reach these individuals.

The World Health Organization stressed that in order to scale up HIV treatment and care, models of service delivery (MOC) that ensure access to treatment for all had to be identified (World Health Organization, 2007: 13, 14). These models would need to take into consideration the realities faced in the developing world, like limited human resources, infrastructure, laboratory services and the availability of drugs (Calmy *et al*, 2004: 2354). Describing functional MOC from settings within the developing world could be a useful standard to develop models of service delivery, discuss ways to achieve universal access to ART, and to have an influence on policies and future program planning (Nelson Mandela Foundation, 2006: i). Four MOC from projects managed by the SACBC were described in Chapters Four, Five and Six. Chapter Seven will summarize the findings of the study and suggest some recommendations for future service planning and policy development.

7.1. The four MOC for ART delivery

The large amount of data presented, together with a review of relevant literature in Chapters Four, Five and Six, makes it difficult to form a clear picture of the different MOC. In order to provide an overview of the four MOC, the main characteristics will be compared and the changes since 2007 will be discussed.

7.1.1. The four MOC

The four MOC were based on projects that provided facility-based care, community-based care, as well as projects that operated in different relations to the SAG. The four MOC discussed were:

- Two projects with different partnership relationships with the SAG
    - ✓ St Apollinaris Hospital, a **public-private partnership** between the SAG and the NGO. The district hospital is based in the Ingwe municipality, Sisonke district of KZN. The NGO provides support to the government MOC; the project is, however, managed by the SAG.
    - ✓ The Bela-Bela HIV & AIDS prevention group (Bela-Bela), a NGO-managed ART project in close collaboration with SAG. The project was located in Bela-Bela municipality in the Waterberg district of Limpopo. The NGO managed the ART project and had a **close relationship** with the on-site SAG managed PHC Clinic.
- Two NGO-managed projects with ART provision points based in different settings
    - ✓ Hope for Life is a facility-based centralized ART project. The project operates in the Tshwane Metropolitan in Gauteng. The project is made up of a group of Catholic HBC-groups that feed into a centralized ART project. HIV care is provided in the community, while ART provision is done at the **centralized ART facilities**.
    - ✓ Tapologo is a Catholic project that provides decentralized ART. The project operates in Rustenburg in the Bojanala district in the North West province. The project is centrally managed (administrative and

logistical support), but provides access to ART at various decentralized ART provision points. HIV care and ART provision is based in the community at **decentralized community-based** points.

The models were compared in detail in Chapters Four, Five and Six. Very few of the differences between the MOC were statistically significant. The Department of Biostatistics at the UFS calculated the confidence interval of 95% to determine the statistical significances of differences between the MOC, and further analyzed whether the data from the districts (from Statistics SA's data) and the projects had similarities, which will now be discussed.

7.1.2. Comparing the MOC

The MOC were compared throughout this document, and, however, many differences were noticed, very few of these differences were statistically significant (95% confidence interval). When comparing the large amount of data generated, the number of differences found with statistical significance seems almost "insignificant". These differences between the projects are reflected in Tables 7.1, 7.2, and 7.3.

The public-private partnership between the SAG and the NGO, St Apollinaris, had the most differences, compared with the others.

St Apollinaris showed the following differences when compared with the three other projects:

- ✓ Younger respondents
- ✓ Respondents lived in the area for longer (most stable population)
- ✓ More people living in the house (larger families)
- ✓ Worse self-perceived health status (see Table 5.37)
- ✓ Took longer to travel to the facility (access to facility)

- ✓ Cost more to travel to the facility (access to facility)
- ✓ CD4 counts were lower at 12 & 18 months (similar at 6, 24, 30 &36)
- ✓ Poorer VL suppression (poorer response to ART)

When compared to specific projects, St Apollinaris showed the following:

- ✓ Hospitalized more than respondents at Hope for Life
- ✓ Hospitalized less than respondents at Tapologo
- ✓ Higher BMI than Tapologo and Bela-Bela

Table 7.1 Statistically significant differences between St Apollinaris and the other three projects

Indicator	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Age of respondents (median)*	35.30 [18.5:66.58]	38.10 [19.07:77.44]	39.56 [19.94:65.77]	39.10 [21.13:75.17]
Living in area (median)*	31 yrs 9 mo [4mo:65yrs]	25 yrs [3mo:77yrs]	21 yrs [3mo:64yrs]	25 yrs [1yrs:74yrs]
# people in the house (median)*	5 [0:24]	3 [0:12]	3 [1:14]	n/a
Health scale (median)*	50 [40:66]	70 [50:89]	69 [50:80]	80 [60:90]
Time to facility (median)*	1 hr 52 min [3min:45hr]	1 hr [5min:20hr]	30min [1min:30hr]	30min [2min:4hr]
Cost for transport (median)*	R17 [0:R150]	R6 [0:R200]	0 [0:R52]	0 [0:R56]
CD4 at 12 months*	240 [137:341]	293 [203:391]	340 [251:474]	311 [200:426]
CD4 at 18 months*	311 [210:393]	367 [255:502]	416 [269:537]	416 [288:559]
BMI baseline*	22.02 [19.68:25.23]	n/a	20.57 [17.47:23.53]	20.13 [18.08:22.57]
BMI 2-3 months*	22.64 [20.57:25.77]	n/a	21.23 [18.52:24.97]	21.18 [19.14:23.59]
BMI 6 months*	23.74 [21.67:26.99]	n/a	22.45 [19.21:26.85]	21.77 [20.13:24.98]
BMI 12 months*	24.22 [21.78:27.63]	n/a	22.70 [19.90:27.59]	22.27 [20.42:24.82]
BMI 18 months*	24.17 [21.63:27.29]	n/a	23.60 [20.15:27.59]	21.88 [20.20:24.78]
# of times hospitalized (maximum)**	3 [1:1:3]	2 [1:1:2]	7 [1:1:7]	n/a
VL 6 months*	<25 [<25:<25]	n/a	<50 [<50:<50]	<50 [<50:<50]
VL 12 months*	<25 [<25:<72]	n/a	<50 [<50:<50]	<50 [<50:<50]
VL 18 months*	<25 [<25:<25]	n/a	<50 [<50:<50]	<50 [<50:<50]
VL 24 months*	<25 [<25:<70]	n/a	<50 [<50:<50]	<50 [<50:<50]
VL 30 months*	<25 [<25:<25]	n/a	<50 [<50:<50]	<50 [<50:<50]
VL 36 months*	<25 [<25:<25]	n/a	<50 [<50:<50]	<50 [<50:<50]

** Lower and upper quartiles in parenthesis; **lower quartiles, median and upper quartile in parenthesis; mo = months; yrs = years; hr = hour; min = minutes

Hope for Life showed the following differences when compared to specific sites:

- ✓ Away from the area less than participants from Bela-Bela (less mobile population)
- ✓ Poorer health scale than Bela-Bela (see Table 5.37)
- ✓ Travelled to facility for longer than Tapologo and Bela-Bela (access)
- ✓ Transport cost more than Tapologo and Bela-Bela (access)
- ✓ CD4 at 12 months less than Tapologo
- ✓ Better BMI than Tapologo at base
- ✓ Better BMI than Bela-Bela at base, 3, 6 and 24 months

Table 7.2 Statistically significant differences between Hope for Life and the other three projects

Indicator	Hope for Life	St Apollinaris	Tapologo	Bela-Bela
Travel away > 1 week	14.29%	n/a	n/a	23.78%
Health scale*	70 [50:89]	n/a	n/a	80 [60:90]
Time to facility (median)*	1hr [5min:20hr]	n/a	30min [1min:30hr]	30min [0min:56hr]
Cost for transport (median)*	R6 [0:R200]	n/a	R0 [0:R52]	R0 [0:R56]
CD4 at 12 months*	293 [203:391]	n/a	340 [251:474]	n/a
BMI baseline*	21.51 [19.28:24.90]	n/a	20.57 [17.47:23.53]	20.13 [18.08:22.57]
BMI 2-3 months*	22.31 [20.08:25.72]	n/a	n/a	21.18 [19.14:23.59]
BMI 6 months*	23.80 [20.55:26.78]	n/a	n/a	21.77 [20.13:24.98]
BMI 24 months*	23.53 [21.52:26.40]	n/a	n/a	21.63 [19.92:24.80]

* Lower and upper quartiles in parenthesis, mo = months, yrs = years, hr = hour, min = minutes

Tapologo showed the following differences when compared with Bela-Bela:

- ✓ Poorer health scale (see Table 5.37)
- ✓ Away from the area less (less mobile population)
- ✓ CD4 at 12 months less

Table 7.3 Statistically significant differences between Tapologo and the other three projects

Indicator	Tapologo	St Apollinaris	Hope for Life	Bela-Bela
Travel away > 1 week	25.52%	n/a	n/a	23.78%
Health scale*	69 [50:80]	n/a	n/a	80 [60:90]
CD4 at 12 months*	240 [137:341]	n/a	n/a	311 [200:426]

* Lower and upper quartiles in parenthesis

There were no further statistically significant differences between Bela-Bela and the other three projects to report.

In comparison, the biggest differences are between the hospital-based model (St Apollinaris) and the clinic/community-based projects (Hope for Life, Tapologo and Bela-Bela). There are, however, advantages and disadvantages to all the models.

St Apollinaris as the traditional (public) rural district hospital had several advantages.

- ✓ Hospital-based ART projects have access to infrastructure (in-patient care, TB diagnostics and treatment, pharmacy and laboratory services etc.) and highly skilled staff on-site.
- ✓ Donor funding improves the project, but does not endanger overall sustainability if such funding is withdrawn.

Disadvantages of the rural district hospital.

- ✓ Is vulnerable to staff turn-over due to rural nature of the hospital. The reliance on doctors initiating patients on ART is problematic as doctors are scarce in rural areas.
- ✓ Facility-based centralized care can become inaccessible to poor patients. Decentralization provided better access to those in need.
- ✓ Community-based support is poor, and can influence adherence and decrease the possibilities of task-shifting.

- ✓ Although CD4 counts were similar and BMI were better at initiation (baseline), the model's respondents had poorer CD4 counts at 12 and 18 months on treatment (than all three the other models) and poorer viral suppression (6-36 months) than Tapologo and Bela-Bela.

Hope for Life as the facility-based centralized ART clinic had an advantage.

- ✓ Community-based support was good and HBC-workers received supervision and support from a registered nurse.

Disadvantages were the following:

- ✓ Is vulnerable due to the reliance on doctors initiating patients on ART. Task-shifting was not utilized well.
- ✓ Facility-based centralized care can become inaccessible to poor patients. Decentralization will provide better access to all those in need.
- ✓ Although CD4 counts were similar and BMI were better at initiation (baseline) the model's respondents had poorer CD4 counts at 12 months on treatment than Tapologo.
- ✓ Model's sustainability cannot be guaranteed beyond donor funding.

Tapologo as the community-based decentralized ART project had the following advantages:

- ✓ Is utilizing task-shifting well. Registered nurses initiate ART while counselors do adherence training. Experienced doctor supports the registered nurses and the IPU.
- ✓ Decentralized ART provision is accessible to poor patients.
- ✓ Community-based support was good and HBC-workers received supervision and support from a registered nurse.

With the following disadvantages:

- ✓ Although CD4 counts were similar at initiation (baseline) the model's respondents had poorer CD4 counts at 12 months on treatment (than Bela-Bela).
- ✓ Model's sustainability cannot be guaranteed beyond donor funding.

Bela-Bela as the facility-based centralized ART project in close collaboration with SAG had the following advantages:

- ✓ Community-based support was good and HBC-workers received supervision and support from a registered nurse.
- ✓ Although CD4 counts were similar at initiation (baseline) the model's respondents had better CD4 counts at 12 months on treatment (than St Apollinaris and Tapologo) and better health status reported (than St Apollinaris, Hope for Life and Tapologo).

With the following disadvantages:

- ✓ Is heavily dependent on doctors, which is not always sustainable due to the shortage of doctors (more so than registered nurses).
- ✓ Facility-based centralized care can become inaccessible to poor patients. Transport was offered to respondents which can be costly.
- ✓ Model's sustainability cannot be guaranteed beyond donor funding.

These models, however, did not remain stagnant over the past couple of years. As they were all managed by the SACBC, "cross-pollination" of ideas occurred.

7.1.3. Changes since 2007

Here follows a list of some of the most profound changes that have occurred at the projects since 2007.

At St Apollinaris:

- ✓ Services were decentralized. ART initiation was initially done at the Hospital, and once stable, the patients were transferred out to one of nine decentralized locations. Five of these locations are based at PHC clinics. Staff at the facilities were supported until they could take over all the services. Hospital staff (registered nurses) still visit these outreach areas to do ART follow-up visits. By June 2011, 3,325 (56%) of the patients initiated at St Apollinaris had been transferred out to local PHC clinics for decentralized care, while more than 300 (5%) of the patients were seen at the four outreach locations.
- ✓ Linkages have been formed with community HCWs in the nearby areas to assist with patient tracing. The community HCW still do not have the support and supervision of a registered nurse.
- ✓ Counselors were deployed to the hospital wards to serve as TB-warriors (lay counselors working in the hospital wards, forming a link between the in-patients and the HIV and TB services).
- ✓ A wellness clinic was started to cater for the needs of HIV-positive individuals not yet eligible for ART.
- ✓ A small pharmacy was opened at the ART clinic to cater for the ART patients' needs.
- ✓ Efforts have been made to integrate the HIV and TB services.
- ✓ A data unit was established at the ART clinic in 2009, using the DoH prescribed registers and the SACBC's prescribed electronic database. The staff ratio of one data capturer for each 500 ART patients has been followed.
- ✓ TB infection control measures were improved throughout at the St Apollinaris hospital and included mechanical ventilation, open window policies, infection control plans, etc.

- ✓ In February 2011, nine registered nurses from St Apollinaris hospital (ART clinic, TB clinic, antenatal care clinic etc.) attended NIM-ART training (see section 6.3.1) and two of the registered nurses working in the ART clinic are now able to initiate ART. Currently there is no doctor available at the ART Clinic.

At Hope for Life:

- ✓ The main Hope for Life Clinic relocated to bigger premises at the St Peter's Church in Winterveldt.
- ✓ An X-ray unit was built on the new premises in order to support TB diagnosis.
- ✓ A small freight container was adapted to function as a laboratory to do basic blood tests (Toga-tainer) on-site.
- ✓ The SACBC's prescribed electronic database was implemented in 2009, with additional data capturers being employed (one data capturer per 500 ART patients).
- ✓ TB infection control measures were improved in 2010, including mechanical ventilation of the environment, the use of open waiting areas, cough officers (lay counselors who ask patients about coughing once they enter the clinic), etc.
- ✓ In February 2011, one registered nurse from Hope for Life attended NIM-ART training.
- ✓ Hope for Life entered into an agreement with the Gauteng DoH; initially DoH ART drugs were provided for all newly initiated patients, and since June 2011, all the patients (1,106) based at the main Hope for Life facility have been receiving SAG funded ART. The 386 patients at the Bertoni satellite are not receiving ART from DoH as the facility is located in the North West Province. The same is true for laboratory services.

At Tapologo:

- ✓ Services have been extended to another four community-based points of service.
- ✓ All the registered nurses based in the community have started to see ART patients and can now initiate patients on treatment.
- ✓ HBC-workers are now paid a salary and their working hours have been extended.
- ✓ A small freight container was adapted to function as a laboratory to do basic blood tests (Toga-tainer) on-site.
- ✓ The SACBC's prescribed electronic database was implemented in 2009 with additional data capturers being employed (One data capturer per 500 ART patients).
- ✓ TB infection control measures were improved in 2010 including open window policies and some mechanical ventilation and open waiting areas, etc.
- ✓ In February 2011, nine registered nurses attended NIM-ART training.
- ✓ Tapologo is currently entering into a service delivery agreement with the local public hospital to become a down-referral clinic for the SAG program, ensuring good care for their patients and ensuring long-term sustainability for the project.

At Bela-Bela:

- ✓ The SACBC's prescribed electronic database was implemented in 2009.
- ✓ In June 2009, SACBC withdrew funding from the ART clinic in Bela-Bela and all the patients were to be transferred out to the local SAG Hospital. It is part of SACBC's sustainability policy to transfer patients to SAG once the SAG facility in the area is able to manage the patients, in order not

to duplicate services. The Bela-Bela group still provides some services on a much smaller scale with privately secured funding. The model as described in this study was, however, not sustainable beyond the SACBC managed funding.

One of the changes that had a profound influence on service delivery at the different projects was the implementation of an electronic database to keep track of the patients in the projects.

The patient data system was developed in-house by the Institute of Youth Development of South Africa and CRS. The database was written in Structured Query Language (SQL) using Visual Basics.NET (VB.net). The system is based around the scheduled visits of the patients. Patients all have a unique identifier. The capabilities of the system are to alert the service provider which patients are due for a visit, what the possible reason for the visit is, and to provide lists of patients who have missed a visit. Furthermore, it enables the service providers to monitor laboratory and pharmacy data. Various reports can be generated to meet the needs of the projects, CRS and the funders. These reports are used to improve patient and overall program management.

These are only some of the most profound changes noticed at the projects. These changes are vital as the changing environment of HIV services necessitates adaptation to remain relevant and effective. Adaptations will have to go beyond only increased access to ART services and nurse initiated ART.

7.2. The changing environment of HIV services

At the turn of the century the general prevalence of HIV among the adult population in South Africa reached 12.9%. At the time, former president Mbeki was consulting with “AIDS experts” regarding whether HIV caused AIDS and assessing alternative treatment for AIDS treatment, as ART was seen as toxic (Swarns, 2000: online). The failure to provide treatment to HIV-infected individuals in developing countries, whilst people in developed countries had access to the life-saving treatment, was declared a global public health emergency in the early 2000s (Fleck, 2003: 698).

Major international donors like the Global Fund (established in 2002) and PEPFAR (announced in 2003) soon stepped up and started funding large HIV projects in developing countries (United States of America, Department of State, 2004: 1; Brown, 2002: online).

The initial responses of international donors were focused on an **Emergency response** to mitigate the consequences of HIV through treatment and care (South Africa and United States of America, 2010: 1). Substantial amounts of money were allocated and hundreds of thousands of individuals were started on ART (PEPFAR, 2010: online). In South Africa, the majority of the services under the PEPFAR grant, were provided by NGOs, private entities and universities, with initially less than 10% of the overall PEPFAR funding going directly to the SAG (South Africa and United States of America, 2010: 6). Furthermore, the key focus of the funding was to address the HIV epidemic, limiting the availability of funding to only HIV and related programs. Due to these specifications, diseases such as TB, STIs and others, could not be addressed in an integrated manner (South Africa and United States of America, 2010: 11). Access to treatment was thus scaled up rapidly through vertical programs.

The Catholic Church was one of the NGOs that responded to the HIV epidemic in South Africa, mainly with PEPFAR funding, by either starting stand-alone services or adding ART to existing HIV projects. Within the program managed by the SACBC AIDS Office, 41,930 individuals were started on ART between

2005 and 2011 (Wilke, 2011: 1), reflecting the rapid scale-up of treatment through mainly vertical systems. These vertical projects thus improved access to HIV care and treatment, but did not support the health system in general.

As shown in this study, the SACBC AIDS Office was able to provide HIV care and treatment in rural areas in innovative ways. The question, six years later, is "*Should we still be providing an emergency response from freight containers?*".

Apart from the concern of the existence of parallel systems run by NGOs, their dependence on donor funding is a concern in light of the global economic crisis. The banking crises in donor countries are associated with substantial declines in aid flows (Dang, Knack and Rogers, 2009: 21; USAID, 2009: 1). The global economic crisis has impacted on all PEPFAR partners (United States of America, Department of State, 2011: online) as it has on recipients of other international donor funding.

In addition to the changes described above, the United States Government (USG) and the SAG have signed a partnership framework in support of South Africa's National HIV & AIDS and TB responses (South Africa and United States of America, 2010). The focus of the PEPFAR funding provided to South Africa between 2012 and 2017 will be to shift the emphasis of the program from an emergency response to building and sustaining health outcomes and systems through a closer alignment with the host country (South Africa and United States of America, 2010: 3). PEPFAR is promoting transition of service delivery responsibility to the local level, supporting leadership by governments and indigenous NGOs. This will translate to an increase of funding from government-to-government resulting in a substantial decrease in funding to the NGO sector.

The SAG is in a better position to take responsibility for the response to HIV than they were in the early 2000s. The initial conditions necessitating the emergency response have changed since the early 2000s. The SAG has made significant gains in their response to HIV since their earlier denial of the disease and the initial slow start. By December 2010, 1.3 million people were on ART and 1,500 health institutions were able to provide ART in South Africa (South Africa, Department of Health, 2011b: online).

The transition from funding NGOs to deliver parallel projects to funding the government directly has certain implications. It may be disastrous if the capacity that has been built in the NGO sector is not harvested. PEPFAR spent more than US$ 3,100 million (R21,700,000,000) between 2004 and 2011 on HIV-related services in South Africa (PEPFAR, 2010: online), and worked through more than 500 prime and sub-partners (South Africa and United States of America, 2010: 6), representing a large investment in the capacity of these partners.

The changing environment for HIV programs can, however, not be ignored. Some of the realities are that:

- ✓ HIV services can no longer be provided in parallel systems,
- ✓ There is a need to move from an emergency response to a response that would allow sustainable strengthening of the health system,
- ✓ The funding environment for HIV in South Africa is changing significantly,
- ✓ NGOs have built capacity in providing HIV services and their experiences could be harvested to benefit future programs and services.

In addition to the above mentioned, the general approach to HIV services can be questioned, as large numbers of individuals have accessed treatment and will need life-long treatment. In order to stay relevant, HIV programs will therefore have to make a paradigm shift towards a chronic care model. As highlighted by the World Health Organization (2006b: 4), *"A new paradigm will dramatically advance efforts to solve the problem of managing diverse patient demands given limited resources. Through innovation, healthcare systems can* *maximize their returns from scarce and seemingly non-existing resources by shifting their services to encompass care for chronic conditions*".

7.3. Chronic care

With the availability of ART, HIV has become a chronic condition that needs to be managed over prolonged periods (Paredes, Sherer and Clotet, 2008: 422; Beck and Walensky, 2008: 56). Chronic conditions are defined as health problems that require ongoing management over a period of years or decades, and include: diabetes, heart disease, asthma, chronic obstructive pulmonary disease, cancer, HIV & AIDS, depression, physical disabilities, etc. (World Health Organization, 2002b: 11).

HIV now joins a growing number of chronic conditions. The prevalence of chronic conditions has increased significantly and is predicted to be the leading cause of disability throughout the world by the year 2020. If not successfully managed, chronic conditions will become the most expensive problems faced by healthcare systems, and the largest health challenge of the century (World Health Organization, 2002b: 26).

The problem is the growing disparity between the chronic care needs of the population and the acute care focus of the healthcare system (Boult, Karm and Groves, 2008: 50; Wagner *et al*, 2001: 64). Healthcare systems are largely built on an acute, episodic MOC that focus on acute problems, urgent needs, and pressing concerns, and are ill equipped to meet the long-term and fluctuating needs of those with chronic illness (Nolte and McKee, 2008: 64; World Health Organization, 2002b: 29; World Health Organization, 2002c: online). As long as the focus of healthcare systems is dominated by an acute care model, health outcomes that otherwise could be accomplished, will be undermined (World Health Organization, 2002b: 38).

Chronic conditions will require the concerted and sustained efforts among decision-makers and leaders in healthcare in every country in the world (World Health Organization, 2002b: 26).

To address the rising rate of chronic conditions, a paradigm shift in the healthcare system is vital. Healthcare systems have to progress beyond the overbearing focus on acute care (World Health Organization, 2002b: 30). Acute care will always be necessary, as even chronic conditions have acute episodes, but at the same time healthcare systems must adapt to care for individuals with long-term health problems. Effective chronic illness management will require a **comprehensive system change that involves more than simply adding new features to an existing acute care model**. Wagner *et al* (2001: 72) stated that changes in the methods and outcomes of healthcare will not occur unless fundamental changes are made to a health system.

Acute care models are unable to meet the needs of patients with chronic illness. Consequently, there is a need for new service delivery models that are characterized by collaboration and cooperation among professionals and institutions that have traditionally worked separately (Nolte and McKee, 2008: 223).

Ground-breaking work on chronic care modeling has been done by Wagner *et al* (2002). The chronic care model, as shown in Figure 7.1, represents a structure for organizing healthcare for chronic conditions.

7.3.1. The Chronic Care Model by Wagner *et al*, *(2002: 70)*.

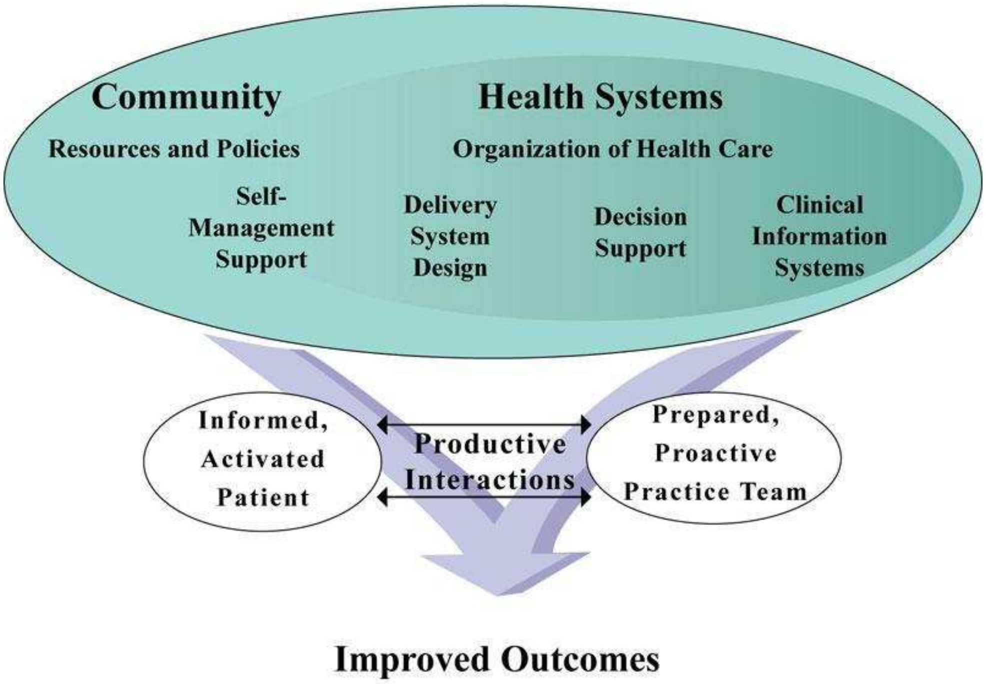


Figure 7.1 The chronic care model (Wagner *et al*, 2002: 70)

The model focuses on linking informed, active people with long-term conditions with pro-active teams of professionals. It acknowledges that a substantial portion of chronic care takes place outside formal healthcare settings and suggests that six elements are of central importance in initiatives to improve chronic care: the **healthcare system; community resources; patient self-management; decision support; delivery system redesign;** and **clinical information systems.** The bottom line is healthier patients, more satisfied providers and cost saving (Improving chronic illness care, 2006a: online; NHS Institute for innovation and improvement, 2006: 5).

This model is the most recognized approach for improving chronic care and has been widely implemented in or used as a guide to redesign or reconfigure healthcare services in numerous countries like the USA, Australia, Canada, England and Germany (Nolte and McKee, 2008: 75; Mechanic, 2004: 2).

Wagner *et al* (2002: 69-71) explain the different elements of the model as follows:

- ✓ The health system is part of the larger community and effective chronic illness management requires an appropriately organized healthcare system linked with the necessary community resources.
- ✓ Helps patients and families with effective self-management support, through collaborative process between patients and providers to define problems, set priorities, establish goals, create care plans, and solve problems through the duration of the illness.
- ✓ Ensure that providers have access to expertise necessary to care for patients (decision support). Evidence-based practice guidelines or protocols can be used to guide providers. Practice teams should also be supported by a specialist.
- ✓ Entails more than merely adding interventions to a current acute care system; it necessitates attention to delivery system redesign. Practice team members need clear, complementary roles. Task-shifting from doctors to experienced registered nurses is required.
- ✓ Timely, useful data about patients and populations from clinical information systems is a critical feature of effective programs.

These elements support the development of both informed, activated patients and prepared, proactive practice teams. Within the productive interaction between the patients and the practice team, functional and clinical outcomes are improved (Wagner *et al*, 2002: 69). The current MOC for HIV services (focused on acute care, based at hospitals, managed by doctors) will have to change if it is to remain sustainable, relevant and effective in the long-term. The researcher will now make some recommendations related to the paradigm shifts needed to change the current MOC.

7.4. Paradigm shift required

The researcher will argue that a dramatic paradigm shift is required to encompass the needs of a growing number of patients with chronic conditions. The required shift of focus, **not a re-engineering of a health system focused on acute care**, will be from:

- ✓ acute care to **chronic care**
- ✓ illness to **health**
- ✓ doctor-focused healthcare to **nurse-driven healthcare**
- ✓ patients being passive bystanders to **patients being active partners** in the health team
- ✓ hospital-based to **community-based settings**
- ✓ HIV services provided as parallel projects to **integrated health services**

7.4.1. Chronic care

Puoane *et al* (2008: 75) concluded in the 2008 *South African Health Review* that chronic diseases contribute a significant proportion to the burden of mortality in South Africa, with HIV & AIDS (25.5%), Ischemic heart disease (6.6%), Hypertensive disease (3.2%), Diabetes Mellitus (2.6%) and Asthma (1.3%) forming the greatest portion thereof.

The challenge to shift from an acute care model to a chronic care model will be daunting. Chronic illness requires complex MOC, involving collaboration among professions and institutions that have traditionally been separate (integration needed). Chronically ill persons struggle with the physical, psychological and social demands of their illness without much help or support from the health system. Current health systems that are focused on care for acute episodes often fail to afford optimal care or to meet the person's needs (Wagner *et al*, 2001: 65). A responsive approach to chronic disease would recognize that chronic disease:

- ✓ Is ongoing, and therefore warrants pro-active, planned, **integrated care** within a system that patients can easily navigate.
- ✓ Involves patients living indefinitely with the disease and its symptoms, requiring them to be **active partners in managing their condition**, rather than passive recipients of care.
- ✓ Requires multi-faceted care which calls for a **team approach**, to meet the wide range of needs of the chronically ill.
- ✓ Can be prevented and therefore warrants **health promotion** and disease prevention strategies (Canada; Ministry of health and long-term care, 2007: 7).

All the MOC in this study focused on acute care, with some promising practices that could be built on with a paradigm shift towards chronic care, such as the utilization of patient education (adherence training) that included health promotion and disease prevention. Task-shifting was used to some extent at all the MOC (more so at Tapologo). The Tapologo model successfully implemented the suggested nurse-managed approach. The MOC, however, lacked the integrated approach and the focus of patients as active partners in managing their condition.

With a chronic care approach, the emphasis of services for the HIV-positive individual will therefore not merely focus on the acute disease (OIs), but will encompass the long-term needs of the individuals and their families. The focus of care will therefore not only be on acute illness, but will include the long-term wellness (health) of the individual.

7.4.2. Focus on health

Health systems do not, in general, promote health, but rather treat the symptoms of an unhealthy lifestyle and disease (Garloch, 2010: online; Richards, 2009: online). In a context of high mortality rates, due to chronic illness, the focus of health systems should shift from illness to health and wellness (Majette, 2011: 370; Garloch, 2010: online; Yukon Registered Nurses Association, 2002: 2). Improving the health of people with chronic illness requires transforming the acute care system to one that is proactive and focused on keeping a person as healthy as possible (Improving chronic illness, 2006b: online).

Chronic diseases are largely due to **preventable** and **modifiable risk factors** such as high blood cholesterol, high blood pressure, obesity, physical inactivity, unhealthy diet, tobacco use, inappropriate use of alcohol and unsafe sexual practices (Puoane *et al*, 2008: 74; World Health Organization, 2002b: 44). The majority of these risk factors can be controlled through comprehensive and integrated actions that focus on health and wellness (Puoane *et al*, 2008: 79). Therefore healthcare should focus on information sharing and support to reduce health risks. Individuals will then be more likely to: reduce substance abuse, stop using tobacco products, practice safe sex, eat healthy foods, and engage in physical activity (World Health Organization, 2002b: 44). This study did not focus on the pre-ART wellness components of the MOC, but rather on the ART provision and therefore does not describe the wellness aspect for patients prior to ART eligibility (section 5.4.2). Adherence training did include topics related to wellness and HIV prevention, as tabulated in Table 5.10 (with a stronger focus on wellness at Tapologo and Bela-Bela). The adherence training aspect can be built on to incorporate patient education into a chronic care model focused on healthcare provision. Current programs, however, still focus on adherence and not on healthy lifestyle. Registered nurses can play a vital role in the provision of chronic care.

7.4.3. Nurse-driven healthcare

In many African settings, HIV services are provided through complex, overburdened delivery systems that require specialist physicians, yet many in need of these services live in rural settings, far from specialized care (Institute of Medicine, 2011: 113). Registered nurses are the largest cadre of HCW in South Africa (and many other African countries) (Stein *et al*, 2008: 8). With registered **nurses** almost exclusively conducting PHC in South Africa, they are **well positioned to manage patients with a chronic condition like HIV** (Long *et al*, 2011: 2; Stein *et al*, 2008: 2).

Registered nurses can, with adequate preparation and support effectively prescribe first-line ART and monitor non-complex patients. Nurse-initiated ART can be a viable strategy for expanding access to ART, even in rural communities (United Nations Program on HIV/AIDS, 2010: 101; Shambusho *et al*, 2009: 8). Allowing ART clinics to be primarily run by registered nurses would significantly enhance the capacity of such clinics, because registered nurses could care for the majority of patients (see Figure 7.2) with minimal supervision (Wester *et al*, 2005: 1043). Furthermore, transferring patients to nurse-managed primary-level clinics also save costs, and will free up the time and resources of doctors and well-equipped facilities to focus on patients who are not responding to treatment or have other complications (Long *et al*, 2011: 8; Horrocks, Anderson and Salisbury, 2002: 819). A combination of trials investigated the registered nurse's role in PHC delivery:

- ✓ Patients were more satisfied with care provided by a well-trained registered nurse,

- ✓ There is no significant difference in patient health outcomes between well-trained registered nurses and doctors,
- ✓ Quality of care is better from well-trained registered nurses, than doctors, in a PHC setting,
- ✓ Well-trained registered nurses provided better patient-focused care and did more investigations to ensure diagnosis was correct than doctors (Support, 2008: 3, 4; Horrocks, Anderson and Salisbury, 2002: 821).

Registered nurses would, however, need to be well-trained and supported for the paradigm shift. Training at the beginning of the 20th century focus on science-based curriculum, by the middle of the century the focus moved to problem-based curriculum, now is the time to focus on system-based curriculum (Frenk et al, 2010: 1924). Currently registered nurses are trained in acute care practice models, chronic diseases, and the skills needed to treat them, are not covered comprehensively in their training (Puoane *et al*, 2008: 81). Training focused on acute care is appropriate for HCWs who diagnose and treat acute health problems; however, acute care skills are necessary, but not sufficient, for managing chronic conditions (World Health Organization, 2002b: 33). Among 134 registered nurses working in ART clinics in the Free State only 47 (35.07%) had training in Clinical Primary Healthcare, a course that is essential to learn to diagnose, treat and care for patients at PHC level (Botma, 2004: 19, 20).

The Rural Health Advocacy Project *et al* (2011: 18) advocate that registered nurses would need specific orientation and training to equip them, as well as ongoing mentoring and support, in order to play a key role in PHC teams as their contribution is pivotal to the successes of future PHC plans. Education authorities have the ability to enhance care for chronic conditions through augmenting HCWs' training. **Pre-service curricula** should be upgraded to better address the needs of patients with chronic conditions (World Health Organization, 2002b: 60). Dr Ruth Stark (2011: interview), a former World Health

Organization Country Director and nurse practitioner trainer in Africa and the Pacific, points out that nurses trained in **specific essential PHC skills** (related to the most prevalent conditions) and provided with **clinical guidelines**, **treatment protocols** and **good clinical supervision** during pre-service training, can successfully manage patients at PHC level.

A further advancement would be to formalize, or legalize, the role of nurse practitioners in South Africa (Geyer, 2009: presentation). Nurse practitioners (also called nurse specialists in South Africa) are nurses who have undergone further training with additional focus on making independent diagnoses and treatment decisions (Support, 2008: 1). Registered nurses already make independent decisions without this type of training and support. The decisions are therefore not always good decisions (Stark, 2011: interview). Nurse practitioners/specialists would, however, be able to lead practice teams in the PHC setting and provide crucial clinical supervision to other cadres. Formal recognition and legal support will, however, be required to establish and sustain these changes in South Africa (Geyer, 2009: presentation).

Countries throughout the world with large nursing workforces and shortages of doctors (especially in rural areas) have chosen to train nurse practitioners/specialists as mid-level practitioners since 1980 (World Health Organization, 2001: 10). The World Health Organization (2001: 10, 11) explains why the organization supports a mid-level practitioner nursing model (instead of a clinician assistant model). Registered nurses are:

- ✓ Already an established category of the workforce of almost every country
- ✓ The largest category of HCWs in most countries
- ✓ Already living and working in underserved areas

- ✓ Already providing a wide range of curative and preventive services in many countries, and
- ✓ A flexible, multi-skilled workforce.

The essential elements of such mid-level practitioner training programs would include:

- ✓ Teaching programs of at least 12 months in length
- ✓ Training focused on essential core content and related clinical competencies
- ✓ Early introduction of practical clinical experience
- ✓ Adequate clinical teaching and supervision
- ✓ Relevant education
- ✓ Doctors involved in teaching and evaluation
- ✓ Teaching faculty maintain clinical skills (World Health Organization, 2001: 14, 15)

Developing and maintaining such practitioners will need legal protection, the use of standard treatment guidelines, on-going clinical supervision, continuing education, career structure and conditions of service and practice (World Health Organization, 2001: 16 - 18).

Within this paradigm shift there will be a need for extensive task-shifting, not only from doctors to registered nurses, but also from registered nurses to lower cadres including community based carers (home-based workers), necessitating a paradigm shift in the roles, support needed and the training of all HCW cadres.

Section 6.3.1 highlights the role of the registered nurses in the different MOC. Tapologo made use of their registered nurses by allowing them to initiate treatment and monitor ART patients while other cadres of HCWs assisted with counseling etc. through task-shifting.

Not all the patients could be managed by registered nurses, but as explained in the next section large numbers of patients can, and should, be managed by registered nurses in community-based (PHC) settings.

7.4.4. Community-based settings

In developing countries, individuals with chronic conditions mainly present at the PHC level, and need to first and foremost be cared for in these settings (World Health Organization, 2005: 47). Delivery of HIV services in rural communities presents unique challenges. Predominant models for ART delivery (hospital-based and doctor-focused) may significantly limit the **accessibility** of services (as described in Chapter Four). *HIV services will have to be decentralized and integrated into the existing PHC system (within a health system focused on chronic care), to have the maximum impact on public health* (World Health Organization, 2010b: online). PHC should therefore be comprehensive, integrated, and the first point of contact for the healthcare consumer (Rural Health Advocacy Project *et al*, 2011: 3).

Apart from the increased access to care, healthcare based in the community-setting (PHC) has the advantage of including **community resources** such as the patients, their families, wider community and NGOs in the healthcare team. When community resources are not utilized in the care of patients with chronic conditions, a broad array of consumer groups, patient advocates, and NGOs, is left virtually untapped. Community resources are critical in resource-poor settings where basic PHC services may be thinly stretched. Community resources can fill the gap in services that cannot be provided by formal healthcare organizations, to greatly enhance the care of patients with chronic conditions (World Health Organization, 2002b: 34).

Tapologo, Hope for Life and Bela-Bela (three NGO-managed projects) had community-based support which was beneficial to the respondents. The HBC provided by the models represented a mix between NGO and FBO models.

Advantages of these models include that they:

- ✓ Provide comprehensive support through community volunteers
- ✓ Are accessible, innovative and flexible
- ✓ Address spiritual and social needs by using existing sustainable networks and volunteers and
- ✓ Provide affordable value for prevention and care (Ogden, Esim and Grown, 2004: 30).

Disadvantages include that they:

- ✓ Do not always have structural links with formal healthcare systems for supplies
- ✓ May be stigmatized, if AIDS-specific
- ✓ Struggle to ensure sustainability and coverage
- ✓ May moralize and increase stigma and
- ✓ May not have the needed skills (Ogden, Esim and Grown, 2004: 30).

Incorporating these community-based projects into the formal health system will capitalize on the advantages while offsetting the disadvantages.

Following these recommendations, more than 80% of individuals with chronic conditions can be managed in the community-setting by well-trained registered nurses, with the support of the community at large (NHS Institute for innovation and improvement, 2006: 12). A schematic outline of the different levels of chronic care is illustrated in Figure 7.2. The diagram is based on the “Kaiser triangle” of different levels of chronic care (NHS Institute for innovation and improvement, 2006: 12). The Kaiser Permanente Hospital follows an innovative approach to provide chronic care to more than 8 million health plan members in the United States (Kaiser Paper Hawaii, 2003: online).

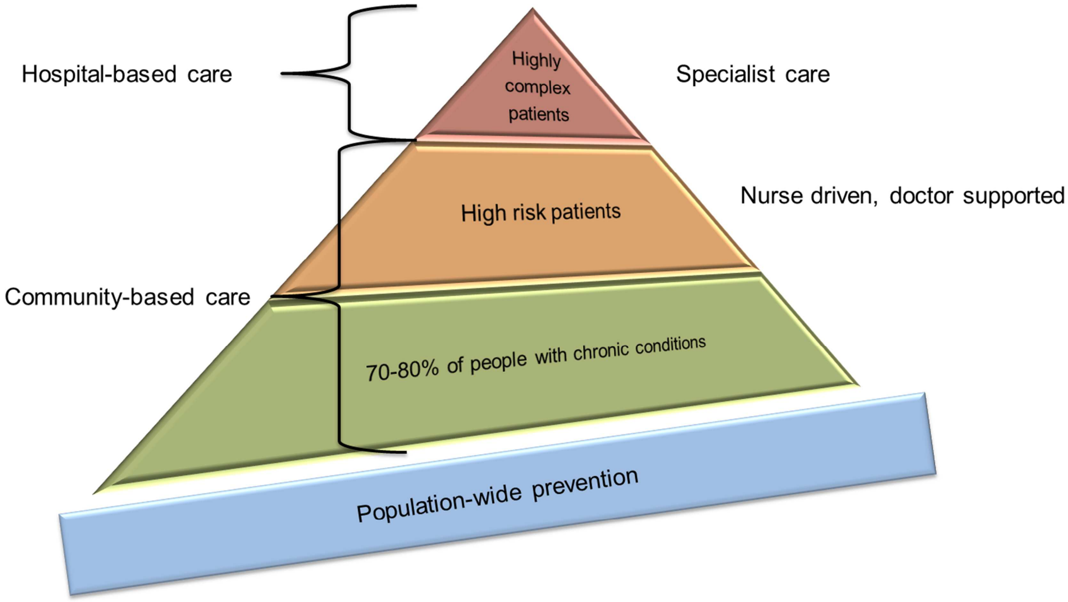


Figure 7.2 The triangle of chronic care, adapted from the triangle by the NHS Institute for innovation and improvement, (2006: 12)

The care triangle can be used to conceptualize chronic care at three main levels, underpinned by population-wide disease prevention and health promotion (Singh, 2008: 4). The three levels are:

- ✓ The majority (70-80%) of people with chronic conditions, who are at low risk of complications and hospitalization, would need self-care support. *This level will include stable, but chronically ill patients that could be managed by registered nurses in the community-based setting, through regular follow-up visits according to standard protocols. The main focus of support would be wellness.*
- ✓ Disease management for people who need regular routine follow-up and are at high risk of complications or death. *These patients can be managed by registered nurses in the community-based setting, while*

supported by a doctor. The main focus of care would be treatment initiation.

- ✓ Case management for people with complex needs who are high-intensity users of planned secondary care. *Care would be provided in a hospital-based setting where specialist care is available* (Singh, 2008: 4).

A key objective is to create a seamless continuum of care for patients from the community-based to tertiary-based care, and back (Rural Health Advocacy Project *et al*, 2011: 5). Decentralized care was demonstrated well at the Tapologo MOC and later implemented at the St Apollinaris MOC. Good examples of community-based support (HBC) was demonstrated at the NGO managed MOC.

When a MOC is based in the community, important stakeholders such as the patient and their family can be engaged more successfully. Throughout the chronic care process the patient (and their family) should be an active participant in the health team.

7.4.5. Patient as active member

Patients and their families are the most undervalued assets in the healthcare system and should be seen as active members of the healthcare team (Canada; Ministry of health and long-term care, 2007: 14). Emphasis must be put upon the patients' central role and responsibilities to adapt their lifestyle and daily behavior change. Any model designed to improve care for chronic conditions should leverage patients' potential (Institute of Healthcare Improvement, 2009: 22; World Health Organization, 2002b: 46), and center care upon their values, preferences, needs and expertise to direct their own care (World Health Organization, 2005: 21).

Current systems downgrade the patient's role, to that of a passive recipient of care, missing the opportunity to engage the patient and their family as important stakeholders (World Health Organization, 2002b: 5). Support for patient self-management should therefore be an important element in any chronic care system, to ensure that patients have the confidence and skills to assume responsibility for their own care, have access to treatment for optimal disease control, work towards prevention of complications, understand the care plan and adhere to follow-up schedules (Kane , 2009: 2338; Blakely and Dziadosz, 2008: 342).

An example would be the way providers interact with patients and their families. The paradigm shift has to be made where patients are no longer told what to do, but are rather involved in the decisions regarding care and empowered to make positive changes in their lifestyle. This is in line with nursing philosophy. As summarized by Cumbie, Conley and Burman (2004: 72) that "*Nursing is guided by a humanistic philosophy wherein persons are regarded holistically rather than biologically, caring is coupled with understanding and purpose; and individual self-determination, independence, and decisional choice in health-related matters are privileged*".

One clear example of the lack of family support is seen in Table 6.6, demonstrating that only two respondents reported any kind of family support during the home visits.

The concern is not only that the patient is not integrated as a stakeholder into the healthcare team, but also that HIV has become a disease treated in vertical systems, as if it is not part of general healthcare.

7.4.6. Integrated HIV care

HIV projects were never intended to be vertical projects. The increased resources allocated to the HIV projects should have "spilled over" and strengthened the health system as a whole (South Africa, National Department of Health, 2003: 95, 103). However, HIV projects were mainly managed as vertical projects with little integration of care (South Africa and United States of America, 2010: 11). Fragmented care distracts the focus from certain health conditions and thin out the available human resources available for general healthcare (Van Rensburg *et al*, 2008; World Health Organization, 2008: 2). The World Health Organization (2008: 1) called for integrated service delivery so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system.

McCoy (2006: 3, 9) calls for a strategy and commitment to change health systems that allow coherent governance and management. Building relationships between NGOs and the public sector will improve the fragmented, incoherent and disorganized state of some healthcare systems (McCoy, 2006: 3, 9). Linking these community-based organizations (NGOs) with SAG-funded ART projects will not only ensure sustainability for the organizations, but will strengthen the SAG projects and ultimately benefit the individuals in need of chronic care as seen in the St Apollinaris MOC.

With the successful paradigm shifts necessary, health systems would be able to adjust and stay relevant to the needs of the population. These paradigm shifts would enable a chronic care model to improve patient outcomes in South Africa.

7.5. A chronic care model for South Africa

The chronic care model by Wagner *et al* (2002) was adapted by the researcher for South Africa, with HIV included as a chronic disease, as illustrated in Figure 7.3. These adaptations were made, based on the findings from this study, the literature reflected in sections 7.3 and 7.4, as well as the recommendations from the World Health Organization regarding chronic care in developing countries.

The World Health Organization's recommendations for effective management of chronic conditions include a paradigm shift, building integrated healthcare, using healthcare personnel more effectively, centering care on the patient and family, and supporting patients in their communities (World Health Organization, 2002d: 4, 5).

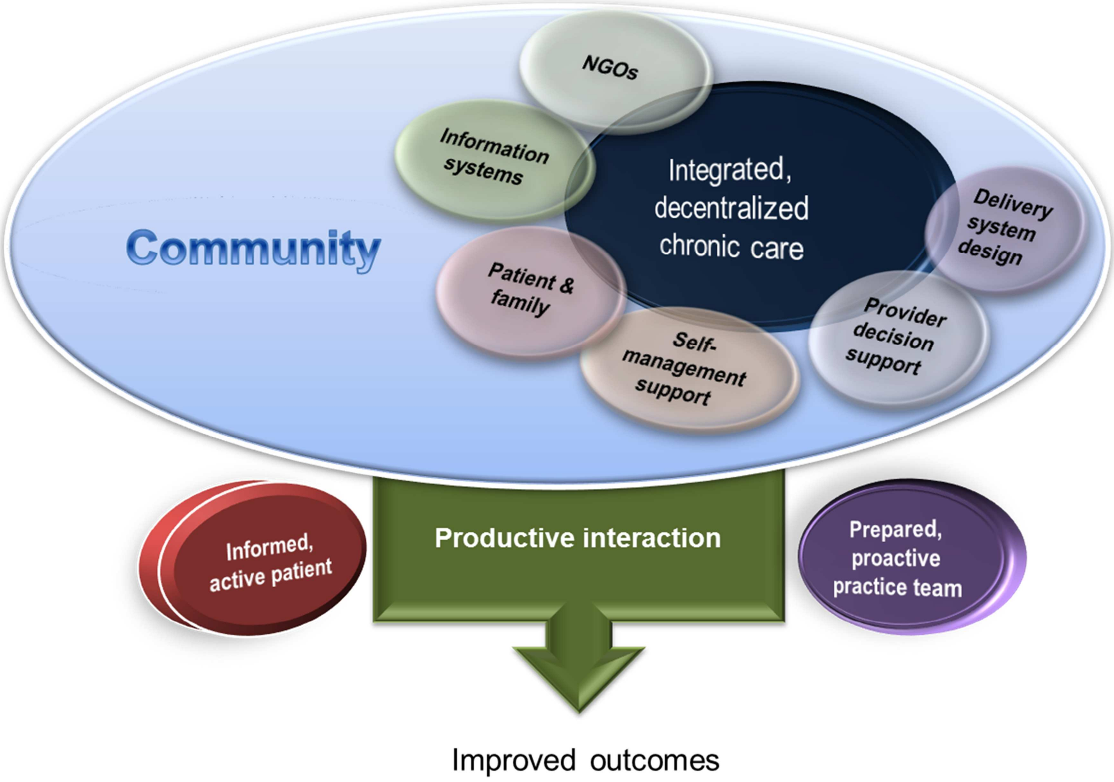


Figure 7.3 Chronic care model for South Africa

The seven elements within the model include:

1) An integrated, decentralized chronic care system based within a primary health setting (community-based). The system is supported by:

2) NGOs
3) an information system (successful use of M&E database)
4) patients and their families
5) self-management support to patients
6) provider decisions support and
7) delivery system redesign.

With this support and the productive interaction between the patient and the practice (health) team, patient outcomes will improve.

7.5.1. An integrated, decentralized chronic care system

In line with the Alma-Ata declaration of 1978, HIV should be included among the chronic conditions managed at a PHC level within the community. The Alma-Ata declaration and the African National Congress' proposed Health Plan in 1994 called for **comprehensive primary health** programs (Dennill, King and Swanepoel, 1999: 16, 17, 42). Comprehensive PHC should work towards changing a community, rather than providing selective PHC that merely focuses on disease control (acute care) (Dennill, King and Swanepoel, 1999: 16, 17). The health system, however, remained plagued by structural and functional fragmentation and the desired integration was not achieved (Sibiya and Gwele, 2009: 32). Apart from the need to provide chronic care (HIV included) in a primary setting, care should be integrated and decentralized.

Integrated care refers to the collaborative efforts and commitment to organize care for patients between different providers (Minkman *et al*, 2011: 1). Different types of integration exist Vertical integration suits the chronic care model best Vertical integration refers to the ability of one provider system to provide all levels and intensities of service by providing a comprehensive package of PHC in one location, in one visit (Sibiya and Gwele, 2009: 35; Sobczak, 2002: 2). There are several desired outcomes to be achieved through healthcare integration: cost control, increase in effectiveness of healthcare delivery, with the necessary change in health service delivery, and program continuity (World Health Organization, 2010b: online).

Decentralizing care into the PHC setting will bring care closer to patients' homes. This will result in a reduction of common barriers such as travel time and cost, increase access, improve retention rates, and enable PHC to become the first-contact point of care (Rural Health Advocacy Project *et al*, 2011: 3; World Health Organization, 2010b: online).

Providing care in decentralized (primary and often rural) settings has been successfully implemented by NGOs like the SACBC. This experience amongst others could be tapped and used to improve the health/treatment outcomes of the patients.

7.5.2. Non-government organizations

NGOs have provided innovative care and have influenced the HIV sphere significantly (De Jong, 2003: 7). This study has documented the successes and contributions of one such program in South Africa. Health systems can benefit from partnering with NGOs as demonstrated by the SAG-managed project (St Apollinaris Hospital). The study further highlighted that many of the capacitated NGOs have the following to contribute to the HIV field:

- ✓ Substantial infrastructure in under-served areas, providing care to some of the poorest individuals in their communities
- ✓ A cadre of skilled people providing treatment
- ✓ A large cadre of home-based workers
- ✓ Ethos of community involvement
- ✓ Functional monitoring and evaluation systems in some instances that assist with patient-, data- and project management

7.5.3. Information systems

Information systems, from paper and pencil records to sophisticated electronic databases, are essential for coordinated, integrated and evidence-informed healthcare (Institute of Healthcare Improvement, 2009: 12; World Health Organization, 2005: 39; World Health Organization, 2002b: 34). With timely data about the patients and their outcomes health practitioners can:

- ✓ Identify patients
- ✓ Facilitate collaboration between team members
- ✓ Improve decisions about care, diagnosis and treatment
- ✓ Track performance for evaluation and continuous quality improvement
- ✓ Implement reminder systems, and follow-up prompts (Canada; Ministry of health and long-term care, 2007: 27)

Without a functional information system, HCWs are reactive rather than proactive when it comes to the needs of patients with chronic conditions (World Health Organization, 2002b: 34). Basic systems need to be put in place with support and training for data capturers. NGOs like the SACBC have experience in this regard and could benefit the health system and improve patient outcomes. Systems developed can be adapted to include other chronic conditions.

The other very important stakeholders that need to be involved in the healthcare team are the patient themselves and their families.

7.5.4. Patients and their families

Patients and their families play a central role in managing their chronic condition and overall wellness (Institute of Healthcare Improvement, 2009: 10). In the African setting, the patient's family and extended family are important role-players in decision making (Van Wyk, 2009a: 55). Incorporating the patients and their family should therefore yield better results and would be more ethical.

HCWs therefore cannot underestimate the importance of the family as a unit (Hattingh, Dreyer and Roos, 2006: 28). According to Hattingh, Dreyer and Roos (2006: 28) HCWs need to: support patients without signs of judgment, focus on incorporating patients as active and equal partners in the effort towards wellness, and support patients' efforts in changing their behavior to manage their chronic condition and improve their health (World Health Organization, 2005: 22). Every member of the healthcare team can support patients and their family to improve the management of their condition.

In the acute care model, HCWs' focus on the clinical outcomes of the patients, while patients and their families have to live with the reality of the condition, experience the uncertainty of life, overcome physical limitation and adapt to the loss of function. Furthermore, the fatigue and stress of coping with the condition and its long-term effects and the need for lifestyle changes, generate further emotional responses. HCWs in a chronic care model would acknowledge the everyday burden of illness and negative emotions that accompany managing chronic conditions. Consequently, patients and their families will feel supported, and would be more willing to collaborate with the HCWs (Institute of Healthcare Improvement, 2009: 10).

In the study it is apparent that disclosure rates are high, which implies available support for the patient. Obtaining support from the family might also pose a valuable opportunity to screen and test the patient's family for related illnesses such as HIV, TB and STIs. The family as a whole will also benefit from the wellness training the patients receive, as many chronic conditions are exacerbated or caused by lifestyle choices. Patients and their families should therefore be active members of the team and should receive essential self-management support to enable them to execute their responsibilities.

7.5.5. Self-management support to patients

As part of the health team, patients and their families' need to be empowered to be part of the team and take responsibility. They need clear information to understand the signs and symptoms of their disease and the treatment they are on. They have to become competent in monitoring their clinical indicators through training and evaluation. Once they understand their illness and are able to monitor and interpret the findings, the patient and family will be able to make behavior changes and sustain them over time (Institute of Healthcare Improvement, 2009: 18).

The idea of patients managing their own health is not a foreign idea. Van Wyk (2009b: 2) explains that in integrative healthcare, it remains the patients responsibility to have their health needs addressed. Patients therefore assume an active role in their own health. Self-management skills will further aid in the prevention and or early detection of predictable complications (World Health Organization, 2005: 17).

In the MOC described in the study, patient education was focused on information regarding treatment, wellness and prevention. Tapologo and Bela-Bela included wellness related topics into their adherence training, while respondents at the other two projects (St Apollinaris and Hope for Life) did not report having received training on wellness related topics at the same levels as respondents at the other two projects (see Table 5.10). Structures for good patient education exist, but staff might need to be re-trained to empower patients and their families. Family support during home visits (see Table 6.6) was very low at all the projects. No self-management topics were mentioned as needs addressed during these interactions. Patient education and community support should thus not only focus on adherence training or support (acute focus), but also emphasize the long-term focus on managing the disease and improving health. Chronic nursing care models, such as Orem's self-care model, should be widely implemented.

7.5.6. Provider decisions support

Staff shortage is a critical concern in healthcare provision (Barnighausen, Bloom and Humair, 2007: 800; Wadee and Khan, 2007: 142). It is critical to adjust MOC to work with the limited staff available, while providing the care needed by the population. An important adjustment is to shift chronic care to a nurse-driven model, where registered nurses have access to **clinical guidelines**, **treatment protocols** and **good clinical supervision**, that extend to include a wider spectrum of aspects required by chronic care patients.

To equip nurses, pre-service training should focus on chronic care provision, while further education of registered nurses to become nurse practitioners/specialists would deliver sufficiently experienced mid-level practitioners who could manage and support lower cadres of HCWs. The majority of chronic care can then be provided by nurses in the community as depicted in the triangle for chronic care used by Kaiser Permanente Hospital (see Figure 7.2).

Reassigning roles by shifting tasks to different cadres of HCWs would also play an important role. It could increase program efficiency, as senior clinical staff have more time to deal with complicated cases, thus saving time and addressing bottlenecks, and increasing access and affordability of chronic care (Challaghan, Ford and Schneider, 2010: 2, 5). Task-shifting would not be limited to shifting tasks from doctors to registered nurses, but include task-shifting to community-based workers (HBC-workers) and even to the patient themselves (making the patient and their family part of the healthcare team).

Team members who are expected to undertake tasks not traditionally part of their scope of practice should, however, receive **supervised clinical training**, have access to **evidence-based guidelines** and **specialist support** (Stark, 2011: interview; World Health Organization, 2002b: 33; World Health Organization, 2001: 8). In light of the shortage of specialists, a resource such as the toll-free National HIV HCW Hotline that provides information to all HCWs in South Africa on aspects concerning the treatment of HIV-infection and related diseases can be utilized (Chisholm *et al*, 2011: 1). Registered nurses can be supported by nurse practitioners/specialists or doctors, while HBC-workers need the same support from a registered nurse. Support provided at Hope for Life and Tapologo to HBC-workers is an important component of the MOC and should be incorporated into the chronic care model.

These paradigm shifts and changes would, however, necessitate a healthcare system redesign in order to have optimal effect.

7.5.7. Delivery system redesign.

The sheer number of people requiring care for chronic conditions (such as HIV) provides unprecedented challenges to the healthcare system. A redesign of the healthcare system, and a reappraisal of the role of registered nurses in the care of these chronic conditions, is required (Institute of Medicine, 2011: 115). The magnitude of the problem necessitates that the majority of chronic care be provided at a PHC level. The World Health Organization (2002b: 4) warns that a primary care system that cannot effectively manage chronic conditions will soon become irrelevant. Complete paradigm shifts would, however, have to be made from the current acute care focus to a chronic care focus. This would entail more than merely adding interventions to the current acute care system; it would necessitate a delivery system redesign (Wagner *et al*, 2002: 69-71).

Some positive changes have been made in the health system since HIV presented in South Africa, but the paradigm shift, from acute to chronic care, has not yet been made.

7.6. Some current developments in health in South Africa

The healthcare scene in South Africa has changed dramatically in the last couple of years with the birth of Democracy and the devastating HIV epidemic. During 2011 several planned changes have been announced by the DoH. Some of these changes are along the line of the above-mentioned recommendations. These are regarding:

- ✓ Integration of HIV into general healthcare
    - o The new NSP 2012-2016 (South Africa, 2011) addresses HIV, TB and STIs as part of an integrative approach (South Africa, 2011: 12). *This could be strengthened if HIV is integrated with other chronic conditions.*
    - o President Zuma announced that all health facilities would be ready to receive and assist HIV patients instead of only a few accredited facilities (South Africa, Presidency, 2011: online). *This would ensure ART is available at each healthcare facility. However, the assurance has not been given that HIV care would be integrated with other programs in the facility.*
- ✓ Decentralization
    - o The Minister of Health announced the re-engineering of the PHC system. The re-engineering program recommends a ward-based team for each municipal ward, strengthening of school health services and the appointment of a district based specialist team (South Africa, Department of Health, 2011a: 6).

  - The NSP 2012-2016 (South Africa, 2011) describes the need to strengthen the PHC system, in line with the PHC re-engineering program, with a focus on the provision of medication at PHC facilities and at household level (South Africa, 2011: 50). The document also mentions the need for an efficient chronic care delivery system (South Africa, 2011: 15). *Although the focus on PHC is promising and would ensure decentralization of services the concern is that the focus of the healthcare is still acute care with curative outcomes, while this study recommends a healthcare re-design with a chronic care approach that focuses on wellness as on well as curative aspects.*

- ✓ Improved cooperation between SAG and NGOs
  - Public healthcare should be provided within the government system or closely linked to it. A positive step in this direction is the commitment of large international funders such as PEPFAR to work closer with the SAG. PEPFAR funded partners' aims to: strengthen the partnership with SAG, reduce duplication of services and increase coverage, strengthen district health systems, shift from direct service delivery to technical assistance, and support the PHC re-engineering from district level (Goldman, 2011: 7).
- ✓ Good information (monitoring and evaluation) systems.
  - The DoH is starting to implement a new National Information System (Tier.net) for HIV to complement the district Health Information System (Anova Health Institute, 2011: 23).
  - The NSP 2012-2016 (South Africa, 2011) sets out to develop a comprehensive monitoring and evaluation system by April 1, 2012 (South Africa, 2011: 16). *These developments are a step in the right direction, but the standardized systems are not widely used yet, and could use the help of experienced NGOs to implement it.*
- ✓ Appropriately trained nurses and adequate clinical support.

- The PHC re-engineering is suggested in the presence of a growing nursing crisis (Schneider, 2011: 8), as it would require an additional 6,000 nurses to implement (South Africa, Department of Health, 2011a: 27).
- The public sector in South Africa alone has a shortage of 40,000 nurses (all cadres). The Minister of Health plans to open 106 nursing colleges in the near future, which could produce lower cadres of nurses in a short period of time (Bhengu, 2011: online).
- The shortage of registered nurses is expected to worsen as the group seems to be much older than other cadres and would need to retire in the next 10-15 years (almost 3,000 per year) (Independent Online, 2011: online).
- In the absence of clear recognition and legislation for different cadres of nurses (such as the nurse practitioner/specialist) the question regarding university training for nurses that has prevailed for more than 60 years continues. Horwitz (2011: 3) describes the tension since the mid-1940s in authorities to decide whether nursing training should be based at university level. Universities clearly produce fewer nurses, as a result of the stringent admission criteria (only 171 B.Sc. Nursing graduates completed the degree at the University of the Witwatersrand between 1969 and the mid-1990s), while they provide enhanced academic training (Horwitz, 2011: 8). *The question should not be whether all nurses should be university trained, but rather how the nursing profession could be structured to encompass all cadres of nurses. Surely as the need for nurses to lead healthcare initiatives increase, the nurse practitioner/specialist would be needed to supervise and support lower cadres of nurses who could provide the necessary care.*

The recommendations in this study will have far reaching consequences for healthcare and the nursing profession in particular if they were to be implemented. The researcher concludes the document with some of these implications.

7.7. Conclusion

Nursing as profession, and the formalization of nurse training (Horwitz, 2011), has undergone enormous developments in the past 130 years in South Africa. Various role-players, like the Catholic Church, have made contributions to these developments. Nurses play (and continue to play) a pivotal role in healthcare delivery with the changing needs of society regarding chronic conditions such as HIV. In order to remain relevant the nursing profession would need to adjust accordingly. Some of the implications for the nursing profession are:

- ✓ Adaptation of models of nursing care for chronic conditions in order to adapt to the context of a growing number of individuals with chronic conditions.
- ✓ Changes in nurse training to focus on wellness (health), involving the patient and their family, and to facilitate patient self-management, through supervised clinical training, access to evidence-based guidelines and specialist support.
- ✓ Recognition and legalization the role of nurse practitioners/specialists in the South African context to lead and support other cadres of nurses.
- ✓ More research to fully explore how to redesign the healthcare system and to establish new training curricula.
- ✓ Development of integrated algorithms for chronic conditions with a focus on optimal health and not merely disease control.

Well trained nurses, utilizing the chronic care model, rather than an acute model of care, can lead to more effective HIV care. Services can be provided as part of PHC services throughout South Africa, providing access to more cost effective care to people, even in the most remote parts of the country.

PART IV

The final part of this document contains the bibliography and annexures of the document in support of the references in the document. Microsoft Word 2010 was used to do the bibliography, using the *Harvard-Exeter* style.

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ANNEXURES

ANNEXURES 1: Approval of ethics committee

Approval letter: Ethics committee

ANNEXURES 2: Permission to conduct the study

Approval letter: SACBC

Approval letter: Siyathokoza

Approval letter: kwaZulu-Natal Department of Health

Approval letter: St Apollinaris Hospital

Approval letter: Hope for Life

Approval letter: Tapologo

Approval letter: HIV/AIDS Prevention Group (Bela-Bela)

ANNEXURES 3: Patient information letter

Patient information letter: English

I, Marisa Wilke, am doing research on the different ways facilities provide antiretroviral treatment to patients. This is part of a research study for academic purposes. You will be asked about yourself and your experiences of using the health facilities supported/linked to by the Catholic Church. The data we obtain will be used to improve of patient services.

Invitation to participate: I would like to ask you to participate in this research study.

What is involved in the study – The information I need for the study will be obtained by an interviewer who will ask you certain questions. We will also look at information, like your blood results and weight in your file if you give us permission. Approximately 850 patients in South Africa will take part in the study; and if all from SA or other countries as well. You will not be rewarded for partaking in the study neither will you be penalised if you choose not to partake in the study.

Risks of being involved in the study: Although this is only a survey, some of the questions relate to personal and sensitive issues. Some people may find it upsetting to recall and discuss their own experiences.

Benefits of being in the study: The benefit of being part of the study is that you will be able to express your experiences in order to help the researcher and the staff to improve patient services.

Participation is voluntary, and if you refuse to participate or decide to terminate participation it will not involve any penalty or loss of benefits to which you are otherwise entitled

Confidentiality: Efforts will be made to keep personal information confidential. Nobody outside the research team will have access to your information. Personal information may be disclosed if required by law.

If results are published, your personal information will not be disclosed. Only information about the group will be disclosed.

Contact details of researcher – Should you require any additional information concerning this study, you may contact the researcher, Marisa Wilke at 082 412 0840 any time if you have questions about the research.

Contact details of REC Secretariat and Chair – You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Patient information letter: Tswana

Nna, Marisa Wilke, ke dira patlisiso mo mekgweng e e farologaneng eo ditheo tsa antiretroviral di fanang ka yona go alafa balwetsi. Se ke karolo ya lenaane patlisiso mo mabakeng a se akademiki.. Otla botswa ka ga wena le maitemogelo a gago a go dirisa ditheo tsa boitekanelo tseo di rotloeditsweng/amagantsweng ke kereke ya katoliki. Dintlha tseo retla di bonang di tla dirisiwa go tokafatsa ditirelo tsa balwetse le maemo a tiro.

Taletso goka tsaya karolo: Ke rata go go kopa go tsaya karolo mo lenaane patlisisong le.

Patlisiso e tsenyeleditse/akareditse eng? – Tshedimosetso eo ke e tlhokang mo patlisisong e tla amogelwa ke mmotsolotsi (interviewer) yo o tla go botsang dipotso tse dirileng. Re tla lekola gape tshedimosetso ya gago, jaaka diteko tsa gago tsa madi le boima jwa gago jwa mmele mo faeleng ya gago fa ore fa tetla. Balwetse bakanna 850 mo Aforika Borwa b atlas tsaya karolo mo lenaane patlisisong. O ka se duelelwe go tsaya karolo mo lenaane patlisisong ebile o ka seka wa otlhaiwa fa o tlhopa go sa tsee karolo mo lenaane patlisisong.

Dikotsi tsa go tsenela lenaane patlisiso: Lefa seno e le tshekatsheko fela, dingwe tsa dipotso diama bowena le mabaka a a masisi. Batho bangwe batla bona fa go kgopisa go gopola le go bua/tlotla ka maitemogelo a bona.

Mesola ya go tsenela lenaane patlisiso: mosola wa go tsaya karolo mo lenaane patlisisong ke gore otla kgona go tlhalosa maitemogelo a gago ele goka thusa mmatlisisi le setheo go tokafatsa ditirelo tsa balwetse le maemo a tiro.

Gotsaya karolo ke boithaopi, ebile fa osa batle go tsaya karolo kgotsa wa tsaya tshwetso ya go kgotlisa/emisa go tsaya karolo ga gona go tsenyeletsa kotlhao epe kgotsa wa latlhegelwa ke dikuno tsa gago tseo ka mabaka-mangwe digo tshwanetseng.

Sephiri/Khupamarama: Go tla tseiwa matsapa goka tshola tshedimosetso ya motho ele sephiri/khupamarama. Ga go kitla go nna le ope yo o kwantle ga setlopha sa babatlisisi yo a tla nnang le tetla ya go bona tshedimosetso ya gago. Tshedimosetso ya motho e tla tswa/senolwa fela fa e tlhokagala go latela molao.

Fa di pholo di phatlhalatswa, tshedimosetse ka ga wena ga e na go senolwa. Tshedimosetso ya setlhopha ke yona fela eo etla senolwang.

Dinomoro tsa go golagana le mmatlisisi - Fa o ka tlhoka tshedimosetso nngwe ee rileng mabapi le patlisiso e, o ka ikgolaganya le mmatlisisi ebong, Marisa Wilke mo dinomorong tse: 082 412 0840 nako ‘nngwe le ‘nngwe fa ona le dipotso kaga patlisiso.

Dinomoro tsa go golagana le mokwaledi le modulasetulo wa REC – O ka ikgolaganya le mokwaledi wa lekgotla la mekgwa ya serutwa sa etikanelo le science, Yunivesiti ya Freistata mo dinomorong tse: 051 405 2812 fa ona le dipotso ka ga ditshwanelo tsa gago jaaka sediriswa mo patlisisong.

Patient information letter: Zulu

Mina, Marisa Wilke, ngeza ucwaningo mayelana nezindlela ezahlukene ezisetshenziswa imitholampilo ukunikezela ngama-antiretrovirals ezigulini. Lolucwaningo luyinxenye yezifundo zami. Uzobuzwa imibuzo emayelana nawe kanye nezimo ohlangabezana nazo ngokusebenzisa imitholampilo exhaswe isonto lase Roma. Ulwazi nemininingwane esiyitholayo izosetshenziswa ekwenzeni kangcono izidingo zeziguli.

Isimemo sokubamba iqhaza: Ngingathanda ukucela ukuba ubambe iqhaza kulolucwaningo.

Lumayelana nani lolucwaningo – Imininingwane engiyidingayo izoqokelelwa yilowo ozobe ekubuza imibuzo ethile. Sizophinde sibheke izinto ezifana nemiphumela yakho yegazi kanye nesisindo sakho, uma usipha ilungelo. Zimalungana ne 850 iziguli lapha eNingizimu Africa ezizobamba iqhaza kulolucwaningo. Angeke uthole lutho ngokubamba kwakho iqhaza futhi angeke ujeziswe uma ungafuni ukubamba iqhaza.

Izinkinga ngokubamba iqhaza kulolucwaningo: Yize lokhu kuwucwaningo nje kuphela, eminye imibuzo iyimfihlo yakho futhi ibucayi. Abanye abantu abakuthandi ukuzikhumbuza kanye nokukhuluma ngezinto ezenzeka ezimpilweni zabo.

Kuzongisiza ngani ukubamba iqhaza kulolucwaningo: Ukubamba kwakho iqhaza kuzokusiza ngoba uzokwazi ukukhuluma ngezinto ohlangabezana nazo lokhu kuzosiza umcwaningi kanye nabasenzi bezempilo ukwenza ngcono izidingo zeziguli.

Uyazikhethela ukubamba iqhaza, futhi uma ungafuni ukubamba iqhaza noma ukhetha ukuyeka phakathi angeke kube nasijeziso futhi angeke ulahlekelwe izinto ofanelwe ukuzithola.

Ukugcinwa kwemininingwane iyimfihlo: Kuzokwenziwa ngayo yonke indlela ukugcina imininingwane yakho ebucayi iyimfihlo. Akekho omunye umuntu uzofinyelela lemininingwane ngaphandle kwalabo abayingxenye yocwaningo. Imininingwane yakho ebucayi kungenzeka ivezwe/yaziswe uma kusho umthetho.

Uma imiphumela ishicilelwa, imininingwane yakho eyimfihlo angeke yaziswe/ivezwe. Imininingwane ezovezwa izobe imayelana neziguli zonke ezibambe iqhaza.

Ukuxhumana nomcwaningi – Uma unemibuzo mayelana nalolucwaningo, sicela uthintane nalomcwaningi, u-Marisa Wilke ku- 082 412 0840 noma ngabe isiphi isikhathi

Ukuxhumana nosihlalo we REC – Ungathintana neNgosi yekomidi elibhekela ukulandelwa kwemithetho engaphansi koMkhakha weZifundo zezeMpilo eNyuvesi yase Free State kulenamba (051) 4052812 uma unemibuzo mayelana namalungelo akho kulolucwaningo

ANNEXURES 4: Patient informed consent

Patient informed consent: English

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe
Faculty of the Humanities

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling
Centre for Health Systems Research & Development

Ref:
Verw: Marisa Wilke (Researcher)

Interview number ……………………………….

CONSENT FORM - PATIENT
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

You have been asked to participate in a research study. Before you decide whether to take part, here is what it involves.

- The researcher is doing research to assess the experiences of people using certain antiretroviral health facilities supported by the Catholic Church. The data we obtain will be used to improve of patient services.
- The information will be obtained by an interviewer who will ask you certain questions.
- Although this is only a survey, some of the questions relate to personal and sensitive issues. Some people may find it upsetting to recall and discuss their own experiences.
- Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.
- If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.
- You are free to stop the interview at any time without affecting future services you receive at any health facility.
- The answers you provide will remain confidential and will not be viewed by any persons or parties not involved in this study.
- Should you agree to participate, we also request consent to access your clinic and hospital records.
- Participants of this study will not receive any reward for participation.
- Should you require any additional information concerning this study, you may contact the researcher, Marisa Wilke at 082 412 0840 any time if you have questions about the research.

- You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

You have been informed about the study by …………………………………… ………………………………..

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

Signature of Participant	Date
Signature of Witness *(Where applicable)*	Date
Signature of Translator *(Where applicable)*	Date

Patient informed consent: Tswana

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref:
Marisa Wilke (Researcher)
Verw:

Interview number ……………………………………

TSWANA CONSENT FORM - PATIENT
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

O kopilwe go tsaya karolo mo lenaaneng la tlhotlhomiso/patlisiso (research study). Pele o tsaya tshwetso ya go ka tsaya karolo, eitse fa e tsenyeleditse tse di latelang.

- Mmatlisisi o dira patlisiso go ka sekaseka maitemogelo a batho bao ba dirang mo ditheong tse dirileng tsa itekenelo ya antiretroviral tseo di rotloeditsweng ke Kereke ya Katoliki. Dintlha tseo retla di bonang di tla dirisiwa go tokafatsa ditirelo tsa balwetse le maemo a tiro.
- Tshedimosetso etla bonwa ke mmotsolotsi yoo tla go botsang dipotso tse dirileng.
- Le fa se ele tlhotlhomiso/patlisiso fela, dipotso dingwe di ama bowena le mabaka a a masisi. batho bangwe batla bona fa go kgopisa go gopola le go bua/tlotla ka maitemogelo ao ba fetileng mogo ona.
- Go tsaya karolo ga gago mo patlisisong e ke boithaopi, ebile gao kake wa otlhlaiwa kgotsa wa latlhegelwa ke dikuno tsa gago fa o gana go tsaya karolo kgotsa wa tsaya tshwetso ya go emisa go tsaya karolo ga gago.
- Fa o dumela go tsaya karolo, otla fiwa kgatiso(copy) e e saenilweng ya tumalano e ga mmogo le lekwalo la tshedimosetso la ba tsaa karolo, eo eleng khutshahatso e e kwadilweng ya patlisiso
- O lokologile go emisa potsolotso nako ngwe le ngwe kwantle ga go ama/tshwaetsa ditirelo tsa gago tsa mo isagong tseo odi bonang mo setheong sengwe le sengwe sa boitekanelo.
- Dikarabo tseo o neelanang ka tsona di tla dula ele sephiri ebile ga dina go bonwa ke mongwe kgotsa makgotla mangwe ao a senang seabe mo patlisisong e.
- Fa o dumela go tsaya karolo mo patlisisong e, re kopa gape tetla ya go bona rekoto ya gago ya tliliniki le ya bookelo.
- Batsaakarolo mo lenaaneng le gaba kitla ba bona tuelo epe go tsaa karolo.

- Fa o ka tlhoka tshedimosetso nngwe ee riling mabapi le patlisiso e, o ka i kgolaganya le Mmatlisisi ebong, Marisa Wilke mo dinomorong tse: 082 412 0840 nako ‘nngwe le ‘nngwe fa ona le dipotso kaga patlisiso.
- O ka ikgolaganya le mokwaledi wa lekgotla la mekgwa ya serutwa sa etikanelo le science, Yunivesiti ya Freistata mo dinomorong tse: 051 405 2812 fa ona le dipotso ka ga ditswanelo tsa gago jaaka sediriswa mo patlisisong.

O itsisitswe ka lenaane patlisiso leno ke …………………………………………………

Fa odumela go ka tsaya karolo, otla fiwa kgatiso(copy) e e saenilweng ya tumalano e ga mmogo le lekwalo la tshedimosetso la ba tsaa karolo, eo ele khutshahatso ee e kwadilweng ya patlisiso

Lenaane patlisiso, ga mmogo le tshedimosetso e e fa godimo ke di tlhaloseditswe ka puisano.

____________________ __________________
Mosaeno wa motsaa-karolo Letlha

____________________ __________________
Mosaeno wa Paki Letlha
(Fa aleteng)

____________________ __________________
Mosaeno wa Moranolodi Letlha
(Fa aleteng)

Patient informed consent: Zulu

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref:
Marisa Wilke (Researcher)
Verw:

ZULU CONSENT FORM – PATIENT
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

Uyacelwa ukuba ubambe iqhaza ocwaningweni, ngaphambi kokuba uvume ukubamba iqhaza, kufanale uqondisise kahle ukuthi lolucwaningo lumayelana nani.

- Umcwaningi wenza ucwaningo ukwazi kabanzi ngezimo noma ngezinto ezihlangatshezwa abantu abasebenzisa imitholampilo enikezela ngama antiretovirals axhaswe isonto lase Roma. Imininingwana esiyotholayo izosetshenziselwa ukuphakamisa izinga losizo olunikezwa iziguli
- Imininingwane izothathwa yilowo ozobe ekubuza imibuzo
- Yize lokhu kuwucwaningo nje kuphela, emiye imibuzo iyimfihlo yakho futh ibucayi. Abanye abantu akukuthandi ukuzikhumbuza kanye nokukhuluma ngezinto ezenzeka ezimpilweni zabo.
- Uyazikhethela ukubamba iqhaza kulolucwaningo, angeke ujeziswe futhi angeke ulahlekelwe yilutho uma ungafuni ukubamba iqhaza noma uyeka phakathi.
- Uma uvuma ukubamba iqhaza, uzonikwa ikhophi yalencwadi kanye nepheshana elinemininingwane mayelana nokubamba kwakho iqhaza, lelipheshana lichaza kabanzi ngocwaningo
- Unalo ilungelo lokuyeka i-interview noma ngabe isiphi isikhathi, lokhu angeke kukhubaze ikusasa lakho mayelana nosizo oluthola kunoma umuphi umtholampilo
- Izimpendulo osipha zona zizogcinwa ziyimfihlo, futhi angeke zibonwe omunye umuntu noma abantu abangasiyo inxenye yocwaningo.
- Uma uvuma ukuba kulolucwaningo, sizocela ukuthi usiphe imvume yokubheka amafayela akho asesibhedlela nawasemtholampilo
- Angeke uthole lutho ngokubamba kwakho iqhaza kulolucwaningo
- Uma unemibuzo mayelana nalolucwaningo, sicela uthintane nalomcwaningi, u-Marisa Wilke ku-082 412 0840 noma ngabe isiphi isikhathi.

- Ungathintana neNgosi yekomidi elibhekela ukulandelwa kwemithetho engaphansi koMkhakha weZifundo Zezempilo eNyuvesi yase Free State kulenamba (051) 4052812 uma unemibuzo mayelana namalungelo akho kulolucwaningo

Uchazelwe kabanzi ngalolucwaningo ngu …………………………………… ……………………………...

Uma uvuma ukubamba iqhaza, uzonikwa ikhophi esayiniwe yalencwadi kanye nepheshana elinemininingwane mayelana nokubamba kwakho iqhaza, lelipheshana lichaza kabanzi ngocwaningo

Ngichazelwe kahle ngalolucwaningo kanye nokubamba kwami iqhaza kulolucwaningo. Ngokuzikhethela, ngiyavuma ukubamba iqhaza kulolucwaningo futhi ngiyaqonda ukuthi kusho ukuthini ukubamba kwami iqhaza.

______________________	___________________
I-signature yophendulayo	Usuku
______________________	___________________
I-signature kafakazi *(uma kufanele)*	Usuku
______________________	___________________
I-signature yotolikayo *(Uma kufanele)*	Usuku

ANNEXURES 5: Staff and HBC-workers’ information letter

Staff and HBC-workers' information letter: English

I, Marisa Wilke, am doing research on the different ways facilities provide antiretroviral treatment to patients. This is part of a research study for academic purposes. You will be asked about your experiences and work conditions at the facilities supported/linked to by the Catholic Church. The data we obtain will be used to improve of patient services and work conditions.

Invitation to participate: I would like to ask you to participate in this research study.

What is involved in the study – The information I need for the study will be obtained by an interviewer who will ask you certain questions (nurses, doctors and managers). Home based carers will be asked to partake in a group meeting. You will not be rewarded for partaking in the study neither will you be penalised if you choose not to partake in the study.

Risks of being involved in the study: Although this is only an interview/discussion some of the questions relate to personal and sensitive issues. Some people may find it upsetting to recall and discuss their own experiences.

Benefits of being in the study: The benefit of being part of the study is that you will be able to express your experiences in order to help the researcher and the facility to improve patient services and work conditions.

Participation is voluntary, and if you refuse to participate or decide to terminate participation it will not involve any penalty or loss of benefits to which you are otherwise entitled

Confidentiality: Efforts will be made to keep personal information confidential. Nobody outside the research team will have access to your information. Personal information may be disclosed if required by law.

If results are published, your personal information will not be disclosed. Only information about the group will be disclosed.

Contact details of researcher – Should you require any additional information concerning this study; you may contact the researcher, Marisa Wilke at 082 412 0840 any time if you have questions about the research.

Contact details of REC Secretariat and Chair – You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

Staff and HBC-workers' information letter: Tswana

Nna, Marisa Wilke, ke dira patlisiso mo mekgweng e e farologaneng eo ditheo tsa antiretroviral di fanang ka yona go alafa balwetsi. Se ke karolo ya lenaane patlisiso mo mabakeng a se akademiki. Otla botsiwa ka maitemogelo a gago mmogo le maemo agago a tiro mo ditheong tseo di rotloeditsweng/amagantsweng ke kereke ya katoliki. Dintlha tseo retla di bonang di tla dirisiwa go tokafatsa ditirelo tsa balwetse le maemo a tiro.

Taletso goka tsaya karolo: Ke rata go go kopa go tsaya karolo mo lenaane patlisisong le.

Patlisiso e tsenyeleditse/akareditse eng? – Tshedimosetso eo ke e tlhokang mo patlisisong e tla amogelwa ke mmotsolotsi (interviewer) yo o tla go botsang dipotso tse dirileng (baoki, dingaka le balaodi). Batlhokomedi ba mo malapeng ba tla kopiwa batla tsaya karolo mo kopanong ya setlhopa. O ka se duelelwe go tsaya karolo mo lenaane patlisisong ebile o ka seka wa otlhaiwa fa o tlhopa go sa tsee karolo mo lenaane patlisisong.

Dikotsi tsa go tsenela lenaane patlisiso: Lefa seno e le potsolotso/puisano fela, dingwe tsa dipotso diama bowena le mabaka a a masisi, batho bangwe batla bona fa go kgopisa go gopola le go bua/tlotla ka maitemogelo a bona.

Mesola ya go tsenela lenaane patlisiso: mosola wa go tsaya karolo mo lenaane patlisisong ke gore otla kgona go tlhalosa maitemogelo a gago ele goka thusa mmatlisisi le setheo go tokafatsa ditirelo tsa balwetse le maemo a tiro.

Gotsaya karolo ke boithaopi, ebile fa osa batle go tsaya karolo kgotsa wa tsaya tshwetso ya go kgotlisa/emisa go tsaya karolo ga gona go tsenyeletsa kotlhao epe kgotsa wa latlhegelwa ke dikuno tsa gago tseo ka mabaka-mangwe digo tshwanetseng.

Sephiri/Khupamarama: Go tla tseiwa matsapa goka tshola tshedimosetso ya motho ele sephiri/khupamarama. Ga go kitla go nna le ope yo o kwantle ga setlopha sa babatlisisi yo a tla nnang le tetla ya go bona tshedimosetso ya gago. Tshedimosetso ya motho e tla tswa/senolwa fela fa e tlhokagala go latela molao.

Fa di pholo di phatlhalatswa, tshedimosetse ka ga wena ga e na go senolwa. Tshedimosetso ya setlhopha ke yona fela eo etla senolwang.

Dinomoro tsa go golagana le mmatlisisi - Fa o ka tlhoka tshedimosetso nngwe ee rileng mabapi le patlisiso e, o ka ikgolaganya le mmatlisisi ebong, Marisa Wilke mo dinomorong tse: 082 412 0840 nako 'nngwe le 'nngwe fa ona le dipotso kaga patlisiso.

Dinomoro tsa go golagana le mokwaledi le modulasetulo wa REC – O ka ikgolaganya le mokwaledi wa lekgotla la mekgwa ya serutwa sa etikanelo le science, Yunivesiti ya Freistata mo dinomorong tse: 051 405 2812 fa ona le dipotso ka ga ditshwanelo tsa gago jaaka sediriswa mo patlisisong.

Staff and HBC-workers' information letter: Zulu

Mina, Marisa Wilke, ngeza ucwaningo mayelana nezindlela ezahlukene ezisetshenziswa imitholampilo ukunikezela ngama-antiretrovirals ezigulini. Lolucwaningo luyinxenye yezifundo zami. Uzobuzwa imibuzo emayelana nawe kanye nezimo osebenza phansi kwazo emtholampilo oxhaswe isonto lase Roma. Ulwazi nemininingwane esiyitholayo izosetshenziswa ekwenzeni kangcono izidingo zeziguli kanye nezimo enisebenza phansi kwazo.

Isimemo sokubamba iqhaza: Ngingathanda ukucela ukuba ubambe iqhaza kulolucwaningo.

Lumayelana nani lolucwaningo – Imininingwane engiyidingayo izoqokelelwa yilowo ozobe ekubuza imibuzo ethile (onesi, odokotela kanye nabaphathi). Onompilo (HBCs) bazocelwa ukuba bahlale ndawonye eqoqwaneni baxoxe. Angeke uthole lutho ngokubamba kwakho iqhaza futhi angeke ujeziswe uma ungafuni ukubamba iqhaza.

Izinkinga ngokubamba iqhaza kulolucwaningo: Yize noma lokhu kumayelana ne-interview/ukuxoxa, eminye imibuzo iyimfihlo yakho futhi ibucayi. Abanye abantu abakuthandi ukuzikhumbuza kanye nokukhuluma ngezinto ezenzeka ezimpilweni zabo.

Kuzongisiza ngani ukubamba iqhaza kulolucwaningo: Ukubamba kwakho iqhaza kuzokusiza ngoba uzokwazi ukukhuluma ngezinto ohlangabezana nazo lokhu kuzosiza umcwaningi kanye nabasenzi bezempilo ukwenza ngcono izidingo zeziguli kanye nezimo enisebenza ngaphansi kwazo.

Uyazikhethela ukubamba iqhaza, futhi uma ungafuni ukubamba iqhaza noma ukhetha ukuyeka phakathi angeke kube nasijeziso futhi angeke ulahlekelwe izinto ofanelwe ukuzithola.

Ukugcinwa kwemininingwane iyimfihlo: Kuzokwenziwa ngayo yonke indlela ukugcina imininingwane yakho ebucayi iyimfihlo. Akekho omunye umuntu uzofinyelela lemininingwane ngaphandle kwalabo aba yingxenye yocwaningo. Imininingwane yakho ebucayi kungenzeka ivezwe/yaziswe uma kusho umthetho.

Uma imiphumela ishicilelwa, imininingwane yakho eyimfihlo angeke yaziswe/ivezwe. Imininingwane mayelana nabantu bonke ababambe iqhaza ezokwaziswa/ezovezwa.

Ukuxhumana nomcwaningi – Uma unemibuzo mayelana nalolucwaningo, sicela uthintane nalomcwaningi, u-Marisa Wilke ku- 082 412 0840 noma ngabe isiphi isikhathi

Ukuxhumana nosihlalo we REC – Ungathintana neNgosi yekomidi elibhekela ukulandelwa kwemithetho engaphansi koMkhakha weziFundo zezeMpilo eNyuvesi yase Free State kulenamba (051) 4052812 uma unemibuzo mayelana namalungelo akho kulolucwaningo

ANNEXURES 6: Staff informed consent

Staff informed consent: English

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref:
Marisa Wilke (Researcher)
Verw:

Interview number ....

CONSENT FORM – HCW
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

You have been asked to participate in a research study. Before you decide whether to take part, here is what it involves.

- The researcher is doing research to assess the experiences of people using certain antiretroviral health facilities supported by the Catholic Church. The data we obtain will be used to improve of patient services.
- The information will be obtained by the researcher who will ask you certain questions.
- Although this is only a survey, some of the questions relate to personal and sensitive issues. Some people may find it upsetting to recall and discuss their own experiences.
- Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.
- If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.
- You are free to stop the interview at any time without affecting future employment at any of the health facility.
- The answers you provide will remain confidential and will not be viewed by any persons or parties not involved in this study.
- Participants of this study will not receive any reward for participation.
- Should you require any additional information concerning this study, you may contact the researcher, Marisa Wilke at 082 412 0840 any time if you have questions about the research.
- You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

You have been informed about the study by …………………………………… ………………………………...

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

______________________ Signature of Participant	___________________ Date
______________________ Signature of Witness *(Where applicable)*	___________________ Date

ANNEXURES 7: HBC-worker informed consent

HBC-worker informed consent: English

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref: Marisa Wilke (Researcher)
Verw:

CONSENT FORM - HOME BASED CARERS
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

You have been asked to participate in a research study. Before you decide whether to take part, here is what it involves.

- The researcher is doing research to assess the experiences of people working at certain antiretroviral health facilities supported by the Catholic Church. The data we obtain will be used to improve of patient services and work conditions.
- The information will be obtained through a group discussion.
- Although this is only a group discussion, some of the questions relate to personal and sensitive issues. Some people may find it upsetting to recall and discuss their own experiences.
- Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.
- If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.
- You are free to stop taking part of the group at any time without affecting future stipends you receive at the facility.
- The answers you provide will remain confidential and will not be viewed by any persons or parties not involved in this study.
- Should you require any additional information concerning this study, you may contact the researcher, Marisa Wilke at 082 412 0840 any time if you have questions about the research.
- You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about your rights as a research subject.

You have been informed about the study by ……………………………………. ………………………………..

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

______________________	___________________
Signature of Participant	Date
______________________	___________________
Signature of Witness *(Where applicable)*	Date
______________________	___________________
Signature of Translator *(Where applicable)*	Date

HBC-worker informed consent: Tswana

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref:
Marisa Wilke (Researcher)
Verw:

TSWANA CONSENT FORM - HOME BASED CARERS
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

O kopilwe go tsaya karolo mo lenaaneng la tlhotlhomiso/patlisiso (research study). Pele o tsaya tshwetso ya go ka tsaya karolo, eitse fa e tsenyeleditse tse di latelang.

- Mmatlisisi o dira patlisiso go ka sekaseka maitemogelo a batho bao ba dirang mo ditheong tse dirileng tsa itekenelo ya antiretroviral tseo di rotloeditsweng ke Kereke ya Katoliki. Dintlha tseo retla di bonang di tla dirisiwa go tokafatsa ditirelo tsa balwetse le maemo a tiro.
- Tshedimosetso etla tswa mo setlhopeng sa poisano.
- Dipotso dingwe di ama bowena le mabaka a a masisi batho bangwe batla bona fa go kgopisa go gopola le go bua/tlotla ka maitemogelo ao ba fetileng mogo ona.
- Go tsaya karolo ga gago mo patlisisong e ke boithaopi, ebile gao kake wa otlhlaiwa kgotsa wa latlhegelwa ke dikuno tsa gago fa o gana go tsaya karolo kgotsa wa tsaya tshwetso ya go fedisa go tsaya karolo ga gago.
- Fa o dumela go tsaya karolo, otla fiwa kgatiso(copy) e e saenilweng ya tumalano e ga mmogo le lekwalo la tshedimosetso la ba tsaa karolo, eo ele khutshahatso ee e kwadilweng ya patlisiso
- O lokologile kgotsa wa emisa go tsaya karolo mo setlhopheng nako ngwe le ngwe kwantle ga go ama/tshwaetsa morokotso wa gago wa isago oo o amogelang mo setheong se.
- Dikarabo tseo o neelanang ka tsona di tla dula ele sephiri ebile ga dina go bonwa ke mongwe kgotsa makgotla mangwe ao a senang seabe mo patlisisong e.
- Fa o ka tlhoka tshedimosetso nngwe ee riling mabapi le patlisiso e, o ka i kgolaganya le Mmatlisisi ebong, Marisa Wilke mo dinomorong tse: 082 412 0840 nako ‘nngwe le ‘nngwe fa ona le dipotso kaga patlisiso.
- O ka ikgolaganya le mokwaledi wa lekgotla la mekgwa ya serutwa sa etikanelo le science, Yunivesiti ya Freistata mo dinomorong tse: 051 405 2812 fa ona le dipotso ka ga ditswanelo tsa gago jaaka

sediriswa mo patlisisong.

O itsisitswe ka lenaane patlisiso leno ke …………………………………………………

Fa odumela go ka tsaya karolo, otla fiwa kgatiso(copy) e e saenilweng ya tumalano e ga mmogo le lekwalo la tshedimosetso la ba tsaa karolo, eo ele khutshahatso ee e kwadilweng ya patlisiso

Lenaane patlisiso, ga mmogo le tshedimosetso e e fa godimo ke di tlhaloseditswe ka puisano. Ke tlhaloganya bokao jwa seabe saka mo lenaane patlisisong le, ebile ke dumela go tsaya karolo ka boithaopi.

____________________	_________________
Mosaeno wa motsaa-karolo	Letlha
____________________	_________________
Mosaeno wa Paki *(Fa aleteng)*	Letlha
____________________	_________________
Mosaeno wa Moranolodi *(Fa aleteng)*	Letlha

HBC-worker informed consent: Zulu

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Fakulteit Geesteswetenskappe **Faculty of the Humanities**

Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling **Centre for Health Systems Research & Development**

Ref:
Marisa Wilke (Researcher)
Verw:

CONSENT FORM - HOME BASED CARERS (ZULU)
MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY

Uyacelwa ukuba ubambe iqhaza kulolucwaningo, ngaphambi kokuba uvume ukubamba iqhaza, kufanale uqondisise kahle ukuthi lumayelana nani lolucwaningo.

- Umcwaningi wenza ucwaningo ukwazi kabanzi ngezimo noma ngezinto ezihlangatshezwa abantu abasebenza emitholampilo enikezela ngama antiretovirals axhaswe isonto lase Roma. Imininingwane esiyitholayo izosetshenziselwa ekwenzeni ngcono izinga losizo olunikezwa iziguli kanye nezimo osebenza ngaphansi kwazo.
- Uzohlangana nabanye abasizi bese nihlala ndawonye ukuze nixoxe ngezinto enihlangabezana nazo.
- Eminye imibuzo iyimfihlo yakho futhi ibucayi. Abanye abantu abakuthandi ukuzikhumbuza kanye nokukhuluma ngezinto ezenzeka ezimpilweni zabo.
- Uyazikhethela ukubamba iqhaza kulolucwaningo, angeke ujeziswe futhi angeke ulahlekelwe yilutho uma ungafuni ukubamba iqhaza noma uyeka phakathi.
- Uma uvuma ukubamba iqhaza, uzonikwa ikhophi yalencwadi kanye nepheshana elineminininingwane mayelana nokubamba kwakho iqhaza, lelipheshana lichaza kabanzi ngocwaningo
- Unalo ilungelo lokuyeka i-interview noma ngabe isiphi isikhathi, lokhu angeke kube namthelela emalini oyithola kulomtholampilo.
- Izimpendulo osipha zona zizogcinwa ziyimfihlo, futhi angeke zibonwe omunye umuntu noma abantu abangasiyo inxenye yocwaningo.
- Uma unemibuzo mayelana nalolucwaningo, sicela uthintane nalomcwaningi, u-Marisa Wilke ku-082 412 0840 noma ngabe isiphi isikhathi.
- Ungathintana neNgosi yekomidi elibhekela ukulandelwa kwemithetho engaphansi koMnyango weZifundo Zezempilo eNyuvesi yase Free State kulenamba (051) 4052812 uma unemibuzo mayelana namalungelo akho kulolucwaningo

Uchazelwe kabanzi ngalolucwaningo ngu ……………………………………. ………………………………...

Uma uvuma ukubamba iqhaza, uzonikwa ikhophi esayiniwe yalencwadi kanye nepheshana elinemininingwane mayelana nokubamba kwakho iqhaza, lelipheshana lichaza kabanzi ngocwaningo

Ngichazelwe kahle ngalolucwaningo kanye nokubamba kwami iqhaza kulolucwaningo. Ngokuzikhethela, ngiyavuma ukubamba iqhaza kulolucwaningo futhi ngiyaqonda ukuthi kusho ukuthini ukubamba kwami iqhaza.

____________________	_________________
I-signature yophendulayo	Usuku
____________________	_________________
i-signature kafakazi *(uma kufanele)*	Usuku
____________________	_________________
i-signature yotolikayo *(Uma kufanele)*	Usuku

ANNEXURES 8: Structured interview guide

Structured interview guide: English (including file audit)

En
English interview guide p 2

English interview guide p 3

English interview guide p 4

English interview guide p 5

English interview guide p 6

English interview guide p 7

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English interview guide p 10

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Structured interview guide: Tswana

Tswana interview guide p 2

Tswana interview guide p 3

Tswana interview guide p 4

Tswana interview guide p 5

Tswana interview guide p 6

Tswana interview guide p 7

Tswana interview guide p 8

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Tswana interview guide p 15

Tswana interview guide p 16

Tswana interview guide p 17

Structured interview guide: Zulu

Zulu interview guide p 2

Zulu interview guide p 3

Zulu interview guide p 4

Zulu interview guide p 5

Zulu interview guide p 6

Zulu interview guide p 7

Zulu interview guide p 8

Zulu interview guide p 9

Zulu interview guide p 10

Zulu interview guide p 11

Zulu interview guide p 12

Zulu interview guide p 13

Zulu interview guide p 14

Zulu interview guide p 15

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Zulu interview guide p 17

ANNEXURES 9: HCW interview guide

HCW interview guide

1. Name of facility.

2. Date of visit.

3. Name of HCW.

4. Position.

5. Consent granted for interview. yes/no

6. Position held.

7. Job description, work experience and training.

8. Daily roles.

9. Major frustrations of current workplace.

10. Describe the admission process to this facility.

11. Describe the usual work-up a client undergoes before ART is initiated.

12. Describe the education and counseling usually done before ART initiation.

13. Describe the education and counseling usually done after ART initiation.

14. How does the pharmacy system work?

15. How is patients supported to adhere to ART?

16. How does the laboratory system work?

17. Describe the chain of referral from this facility.

18. Anything else?

ANNEXURES 10: Facility assessment interview guide

Facility assessment interview guide

A: SITE AND VISIT DETAILS

1. Name of facility.

2. Date of visit.

3. Interview held with:

B: PHYSICAL SPACE AND LOCATION

4. Describe the facility structure and its location.

5. Mention how the facility is situated relative to public transport routes.

6. Make a brief assessment of what activities occurs where:

- ✓ How many clinical consultation rooms?
- ✓ How many counseling rooms?
- ✓ Describe the waiting area.
- ✓ Other comments regarding infrastructure (take photos)

8. How long has the facility been operational?

9. How many days per week is the facility open?

10. How many hours per week is the facility open?

11. Describe the background of the facility.

C: STAFF STRUCTURE

12. Indicate the staff complement in the table below

Staff member		**Training**	**Manager**	**Funded by**
Managerial	Manager			
Clinical	Doctor			
	Nurse			
Support	HBC			
	Counselors			
Admin	Clerk			
	Data capturer			

13. Notes to the table above (include management and support structures).

D: PROTOCOLS, GUIDELINES AND STANDARD OPERATING PROCEDURES

14. Do clear, accessible guidelines exist for each/any of the following?

- ✓ Staff roles
- ✓ Reporting procedures for staff grievances
- ✓ HIV care guidelines
- ✓ Indication for ART
- ✓ What regimen is indicated
- ✓ ART counseling guidelines
- ✓ Blood tests to be performed for patients on ART

E: CONTINUUM OF CARE

15. Does the facility offer?

Type of service	Yes	No	If no, where could a client access the service?	How could a client access the service
VCT				
Pre-ART services				
TB diagnosis				
Antenatal care				
Pediatric ART				
STI treatment				
PHC				
Contraception				

16. Describe the admission process to this facility.

17. Describe the flow of an HIV-positive person through the facility.

18. Describe the usual work-up a patient undergoes before ART is initiated (medical assessment, education and counseling, decision to initiate ART, pharmacy procedures, laboratory tests etc.)

19. Describe the usual process initiation of patients on ART.

20. Are there community-based adherence supporters (describe)?

21. Are there support groups for patients at the facilities (describe)?

22. Describe the adherence techniques used.

F: INFORMATION MANAGEMENT

23. In what format are clinical notes recorded?

24. Describe the process of data collation, verification and reporting.

25. Describe the process of folder management.

26. Is the information system computerized?

G: LABORATORY SERVICES

27. Describe the laboratory services:

- ✓ Tests available
- ✓ Transport process to laboratory

H: PHARMACY SERVICES

28. Describe the pharmacy services:

- ✓ Regimens available
- ✓ Prescription of ART
- ✓ Dispensing of ART

I: LINKS WITH OTHER SERVICES

29. Describe the chain of referral from the facility.

30. Are there links between the facility and the SAG (describe)?

31. Is there links with a HBC group? If so, describe:

- ✓ Relationship with ART clinic
- ✓ Supervision of HBC-workers
- ✓ Support available for HBC-workers
- ✓ Remuneration of HBC-workers

32. Any other comments?

ANNEXURES 11: Nominal group question

Nominal group question: English

What do you need to be a good HBC-worker?

Nominal group question: Tswana

O nagana ke eng se se dirang molekodi (HBC-workers) yo ikanyegang yo o botlhokwa?

Nominal group question: Zulu

Ucabanga ukuthi yini ekwenza ukuthi ube HBC exotho?

ANNEXURES 12: Nominal group data

Table 9.1 Theme 1: Support networks

Group	Statement	Score							
1	Counseling the HBC-worker	4	2	5	3	2	3	2	5
2	HBC-worker Counsel the patients and families. Also needs counseling.	1	4	2	1	3			
2	The patients love the HBC-worker	1	1						
3	Monthly meetings, to discuss challenges and give each other support.	1	2	2	3				
3	Caring together as HBC-worker. Attend debriefing sessions and talk about challenges	1	1	3					
4	Support for HBC-worker. Care of the carer	4	3	5	4	3	4	2	3
4	Spiritual counseling (debriefing). Stress relief sessions. Prayer	3	2	2	1	5			
5	Counseling the HBC-worker. Workshop for the HBC-worker. Confidentiality for HBC-worker.	4	2	4	3	3	2	5	
5	People helping each other (HBC help others). Relationship with community.	3	5	3	5				
5	Volunteer (no pay). My feelings (feel free). Love for the patient. Sympathy for the patient	5	1	4	2	4	4	5	
5	My family. My HBC family.	1	4	3	5	1	1		
5	Church	2							
6	Friendship with patient, other HBC-worker. HBC-worker trust, love and care for each other.	2	1	2	3	3	4		
6	Prayer	5	4	5	1	5			
6	Volunteer (no pay, be there for others). Cooperation between patients, community and HBC. Communication with patients and family.	1	2	1					
7	Church and Justice and peace	4	1						
8	Love for patients. Family (own) supports HBC-worker. Respect from community. Appreciation from community. Children (own support HBC-worker).	2	4	3	3	5			
8	Church (spiritual and practical support). Community appreciates and assists.	1	4	5	3	2			
9	Church (donation and support). Prayer.	5	5	4	4	5	5	5	5
9	Patients (help each other and condition improve).	4	3	1	3	4	4		
9	Community (refers and support). Patient's neighbors (support)	1	1	3					
10	NGO (assist, training)	2	5						
12	Patients' family support HBC-worker. Pray for the patients. Church (donates and support).	2	5	5	1	5			

Table 9.2 Theme 2: Aptitude

Group	Statement	Score							
1	Love to look after the sick; must bath the sick	4	5	5	2	4	3	5	5
4	Problem solving	4							
5	Determination. Motivation (always have hope).	3	3	1	1	2	4	3	
6	Sympathy for the patient	3	2	3	5	3			
6	Compassion. Caring for family too. Love the job and sick.	4	5	5	2	3			
6	Get encouragement (patients improve). Have to support (patient, HBC and family).	1	5	1	2	2	4		
6	Keep busy.	5	3	1					
8	Self-motivation (love your job)	5	2	2	1				
9	Love/happiness.	4	5	3	1	2	1		
9	Counsel patients	1	5	3	2	1	2	4	
10	Personal appearance. Counseling skills. Personal conduct. Respect for others. Good behavior. Appropriate approach to others (attitude). Support (active involvement). Confidence. Communication with patients and collogues.	5	3	2	1	3	4		
10	HBC-worker's responsibility (have what needs to do work).	4	5	4	1	2			
11	Smile with patients. Joking.	5	3						
11	Not to shout at patients. Proper communication.	1	1	2	1				

Table 9.3 Theme 3: Continuum of Care

Group	Statement	Score							
1	Community doesn't want HBC to visit the sick. The family doesn't treat the patients well.	3							
3	HBC-worker to follow-up drug adherence at patient's home. Patient food parcels. Taking care of the patients. Visiting once a week	2	4	5	2	5			
3	Need a doctor	5	5	5	4	5	5	3	
4	Behavior change due to ART (positive)	1							
5	Hospice (die with dignity/get better). Ill patients (thy get better).	2	5	5	2	2	4		
5	To see the patient getting help/service from HBC. Give advice to support to patient.	1	1						
6	Family of patient; give info. Get to know them	2							
7	Hospice (refers sick patients and gets food). NGO clinic (provide free services). SAG clinic (complimentary services).	3	2	4	3	5	3	3	
8	NGO clinic (assists with food). Hospice (admit the sick, work experience, pay).	1	4						
9	NGO PHC clinic (refer and treat).	3	2	2	3	4	3	2	
9	Family of patient give advice, assist patient, lifestyle	2	2	1					
10	SAG clinic (refer and complementary services). Social workers (Social services). Patient responsibility. Patient's family. Hospital (should assist with ill patients). Wellness clinic (pre ART services). ART (improve health). Patient's adherence (patient's	3	4	5	5	1			
10	Motivate patients and family to take ART.	5	4	5					
10	Community (refers and support).	1	3						
11	Home visits to patients. Patients to take treatment on time and properly.	3	3	3	5	5			
12	Bath the patients. Cook for the patients. See to it that the patients take ART correctly. Clean pillbox. Wash clothes. Treat the patients well. Complete the patient forms. Encourage patients. Remind patients of doctor’s appointments	3	5	2					
12	Patient and HBC-worker must be clean.	4	5						
12	Campaigns (mass). Door to door campaigns. DOTS supporter	4	3	3	4				
12	NGO and SAG clinics in collaboration provide services. HBC-worker translates for HCWs.	1	1						

Table 9.4 Theme 4: Remuneration

Group	Statement	Score							
1	Use our own money. Money for thank you. Other volunteers get paid and look down on us	3	5	3	4	2	1	4	5
2	Christmas prizes for HBC-worker and patients	4	4	1	2	1	1		
2	Money for HBC work	5	5	5	5	4	5	5	5
4	Finance (stipends revised). Stipends are low. Life cover for HBC-worker	2	5	4	5	1	5	2	3
6	Money (for assisting patients and communication)	3	3	4	4	4	4		
7	Money (for patients needs and HBC as remuneration)	4	5	3	5	4	5	5	
10	Stipends (remuneration).	4	2						

Table 9.5 Theme 5: Skill building

Group	Statement	Score							
1	Workshops for the HBC-worker	1	3	5	2	3			
2	Training for HBC-worker	4	2	3	2	2	2		
3	Workshops for the HBC-worker	4	2	2	3	5	2	3	
4	Workshops for the HBC-worker	4	1	3	3				
6	Information (learn more)	4	2	1	1	5			
8	Knowledge (workshops)	3	3	5	2	4	3	4	2

ANNEXURES 13: HCW data

Table 9.6 The role of the registered nurse (Table 6.4)

HCW	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Nurse 1	1. Admit patients to the ART clinic 2. Take blood 3. Do consultation 4. Prescribe OI medication 5. Do counseling 6. Supervise other cadres 7. Patient health education 8. Order stock 9 Document care	1. Provide health education 2. Admit patients to ART clinic 3. Do consultations 4. Take bloods 5. Do counseling 6. Assist with grant applications 7. Prescribe OI medication 8. Document care	1. Admit patients to ART clinic 2. Do consultations 3. Draw blood 4. Prescribe OI medication 5. Do counseling 6. Supervise/assist HBC-workers with home visits 7. Do home visits 8. Provide health education 9. Document care 10. Do nursing care plans	1. Do home visits 2. Do adherence preparations 3. Translate for doctor
Nurse 2	1. Do consultation 2. Take blood 3. Prescribe OI medication 4. Do counseling 5. Patient health education 6. Document care	1. Provide health education 2. Admit patients to ART clinic 3. Do consultations 4. Take bloods 5. Do counseling 6. Assist with grant applications 7. Prescribe OI medication 8. Document care 9. Order medication	Same as nurse 1	
Nurse 3	Same as nurse 2	HBC-nurses supervise HBC-workers (not interviewed)	Same as nurse 1	
Nurse 4			1. Do consultations 2. Draw blood 3. Prescribe OI medication 4. Initiate ARV 5. Do counseling 6. Provide health education 7. Document care	
Nurse 5			Same as nurse 1	
Nurse 6			Same as nurse 1	
Nurse 7			Same as nurse 4	

Table 9.7 Major frustrations – nurses (Table 6.16)

Interview	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Nurse 1	1. Very sick patients 2. Pediatric patients (grannies struggle) 3. Cultural influence men not involved) 4. Patients default (women) 5. Occupational compensation 6. Space in clinic	1. Very high workload	1. HBC-workers limited hours 2. Not all nurses committed	1. None
Nurse 2	1. Patients very poor, no food 2. Cultural influence (men do not consent to women taking treatment) 3. Clinic not open on weekend 4. Problems with pharmacy 5. Shortage of staff	1. Space in clinic limited	1. Very ill patients 2. Very mobile population 3. Patients do not have food 4. Hospice (IPU) sometimes full 5. Patients very poor	
Nurse 3	1. Lack of support from top management 2. Staff shortage 3. Unemployment high in area 4. Limited space in clinic		1. Facility far, patient walks 7 km 2. Space in clinic limited 3. infrastructure in clinic limited 4. Patients default due to grant, choose grant over treatment 4. Staff travel far to clinic	
Nurse 4			1. Space and infrastructure in clinic limited	
Nurse 5			1. Staff travel far to clinics	
Nurse 6			1. Patients very poor, no food at home 2. Infrastructure at clinic limited	
Nurse 7			1. Patients very poor, no food at home 2. Patients default due to grant	

Table 9.8 Major frustrations – doctors (Table 6.16)

Interview	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Doctor 1	1. Staff shortage 2. Lack of support from management		1. None	1. TB is a big problem 2. Long-term side effects is a worry
Doctor 2				1. Language barriers

Table 9.9 Major frustrations – other (Table 6.16)

Interview	St Apollinaris	Hope for Life	Tapologo	Bela-Bela
Other 1	1. Very sick patients 2. Patients who default 3. Cultural influences (men do not consent to wife taking ART)	1. Patients very poor 2. Patient have no food 3. Patients on treatment for long time, default when better	1. Crime in area high 2. Space limitation at clinic	1. Space in clinic limited. 2. Very high workload
Other 2	1. Staff shortage 2. Lack of support from management	1. Space in clinic limits 2. Adolescent care difficult		

ABSTRACT

MODELS OF CARE FOR ANTIRETROVIRAL TREATMENT DELIVERY: A FAITH-BASED ORGANIZATION'S RESPONSE

Keywords: access to antiretroviral therapy, antiretroviral therapy services, Catholic healthcare, chronic care model, community-based support, history of faith-based healthcare, human immunodeficiency virus, faith-based response to health, models of care, nurse specialists, patient profile, role of nurses.

Background: Since 1849, Catholic religious have provided health services in South Africa. They have established hospitals, clinics, and have provided community-based preventive and curative services throughout the country. Today faith-based organizations (FBOs) continue to play an important role in healthcare delivery and are crucial to the goal of providing universal access to antiretroviral therapy (ART). In order to scale up HIV care and treatment, there is a need to describe and analyze ART models of care (MOC) that address the challenges faced by developing countries. The South African Catholic Bishops' Conference (SACBC) manages twenty ART clinics in medically underserved South African communities, where the need is great, but the resources limited. These SACBC managed ART clinics operate on different MOC. A study to describe, analyze and compare the different MOC can inform future directions in healthcare delivery in resource-constrained settings.

Method: A single case-study design was used to describe, analyze and compare four different MOC (managed by the SACBC) for ART delivery, as embedded units of analysis. A mixed method approach was used, incorporating qualitative and quantitative information. Data were collected using structured interviews (n=1,006 adult ART patients), file audits (n=1,006 files of the respondents), semi-structured interviews (n=27 healthcare workers) and nominal groups (n=12 groups with

Home Based Care-workers). Descriptive and inferential data analyses were conducted by a biostatistician from the Department of Biostatistics at the University of the Free State and the researcher.

Findings: In the study, patients accessed care late (CD4=119 cells/mm^3). Decentralized care provided better access. Family members are a potential source of support because disclosure rates to relatives and others were high (95.63%). Nurse-driven, doctor supported care was not inferior to doctor-driven care. Task-shifting to registered nurses and HBC-workers can be implemented successfully with support. Differences exist between the South African Government (SAG) -managed model and the FBO–managed models. Partnership between the SAG and FBO strengthened the SAG-managed MOC, while capitalizing on the sustainability of the government services. Functional information systems, developed by the FBO, were implemented at all the MOC in 2009. All the MOC focused on acute care.

Conclusions: Nurse-driven decentralized service can most effectively and appropriately address the chronic nature of HIV and strengthen the healthcare system by a paradigm shift to a chronic care model. Based on the findings, a chronic care model was adapted for South Africa that has seven elements: (1) an integrated, decentralized chronic care system based within a primary health setting; (2) partnerships with NGOs; (3) an effective information management system; (4) patients and their families; (5) self-management support to patients; (6) provider decision support and (7) delivery system redesign. Implications for the nursing profession include adaptation of focus and training, as well as the recognition of the nurse practitioners/specialist role in South Africa.

OPSOMMING

SORGMODELLE VIR DIE LEWERING VAN ANTIRETROVIRALE BEHANDELING: RESPONS VAN ‘N GELOOFSGEBASEERDE ORGANISASIE

Sleutel woorde: antiretrovirale dienste, geloofsgebaseerde gesondheidsorg, gemeenskapsgebaseerde ondersteuning, geskiedenis van geloofsgebaseerde gesondheidsorg, Katolieke gesondheidsorg, chroniese sorgmodel, menslike immuniteitsgebreksvirus, pasiëntprofiel, rol van die verpleegkundige, toegang tot antiretrovirale behandeling, verpleegspesialiste.

Agtergrond: Katolieke geestelikes het reeds sedert 1849 gesondheidsorg in Suid Afrika voorsien. Hulle het hospitale en klinieke opgerig en gemeenskapsgebaseerde voorkomende en kuratiewe dienste regdeur die land gelewer. Vandag speel geloofsgebaseerde organisasies (GGOs) steeds ‘n belangrike rol in gesondheidsorg en lewer sleutelbydraes om universiele toegang tot antiretrovirale behandeling (ARB) te verseker. Ten einde die voorsiening van menslike immuniteitsgebreksvirus (MIV)-sorg en ARB te versnel, is daar ‘n behoefte om antiretrovirale sorgmodelle (ASM), wat die uitdagings in ontwikkelende lande aanspreek, te beskryf en te ontleed. Die Suider-Afrikaanse Katolieke Biskoppe Konferensie (SAKBK) bestuur twintig ARB-klinieke in medies-onderbediende Suid-Afrikaanse gemeenskappe, waar die behoeftes die beskikbare hulpbronne ver oorskry. Die SAKBK se ARB-klinieke implimenteer verskillende ASM. ‘n Studie om hierdie verskillende ASM te beskryf, te ontleed en te vergelyk kan toekomstige gesondheidsorg in hulpbron-beperkte omgewings inlig.

Metode: ‘n Enkele gevalle-studieontwerp is gebruik om vier verskillende ASM (deur die SAKBK bestuur) as ingebedde ontledingseenhede te beskryf, te ontleed en te vergelyk. ‘n Gemengde metode-benadering is gevolg waarin beide

kwantitiewe en kwalitatiewe inligting gebruik is. Inligting is deur middel van gestruktureerde onderhoude (n=1,006 volwasse ARB pasiënte), lêeroudits (n=1,006 lêers van respondente), semi-gestruktureerde onderhoude (n=27 gesondheidswerkers) en nominale groepe (n=12 groepe met tuisversorgers) ingewin. Beskrywende en inferensiële data-ontledings is deur 'n biostatikus van die Departament van Biostatistiek aan die Universiteit van die Vrystaat en die navorser uitgevoer.

Bevindinge: Pasiënte met gevorderde siektetoestande (mediaan CD4=119 selle/mm^3 by inisiasie) het op 'n laat stadium vir sorg aangemeld. Gedesentraliseerde sorg het beter toegang gebied. Familielede is 'n potensiële bron van ondersteuning, aangesien 'n hoë persentasie pasiënte (95.63%) hul MIV-status aan familielede bekend gemaak het. Verpleegkundig-gedrewe, dokter-ondersteunde sorg is nie van minder waarde as dokter-gedrewe sorg nie. Delegering van take aan verpleegpersoneel en tuisversorgers kan, met die nodige ondersteuning, suksesvol geïmplementeer word. Verskille bestaan tussen die Suid-Afrikaanse regering (SAR)-bestuurde model en daardie modelle wat deur die Katolieke Kerk bestuur word. Die vernootskap tussen die SAR en Katolieke Kerk (GGO) het die SAR-bestuurde model versterk, terwyl voordeel uit die volhoudbaarheid van regeringsdienste getrek is. Funksionele inligtingbestuursisteem wat deur die GGO ontwikkel is, is in 2009 by alle ASM geïmplimenteer. Al die bestudeerde ASM het op die lewering van akute sorg gefokus.

Gevolgtrekkings: Verpleegkundig-gedrewe, gedesentraliseerde dienste kan die chroniese aard van MIV op die effektiefste en toepaslikste wyse aanspreek, en die gesondheidsorgsisteem versterk by wyse van 'n paradigmaskuif na 'n chroniese sorgmodel. Na aanleiding van die bevindinge is 'n chroniese sorgmodel, met sewe elemente, aangepas vir Suid Afrika: (1) 'n geintegreerde, gedesentraliseerde, kroniese sorgsisteem binne 'n primêre gesondheidsorgomgewing gestel; (2) vernootskappe met nie-regerings organisasies; (3) 'n doeltreffende inligtingsbestuursisteem; (4) pasiënte en hulle familie; (5) self-bestuurondersteuning aan pasiënte; (6) ondersteuning van verskafferbesluitneming en (7) die herontwerp van diensleweringsisteem. Implikasies vir die verpleegprofessie behels, sowel aanpassing van fokus en opleiding, as die erkenning van die rol van die verpleegpraktisyn/ spesialis in Suid Afrika.