

**MET AND UNMET PALLIATIVE CARE NEEDS
FOR PEOPLE LIVING WITH HIV/AIDS IN
SELECTED AREAS IN RWANDA.**

By

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degree of Masters of Science in the Department of Physiotherapy,
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ABSTRACT

According to UNAIDS, in 2003, 495,000 of the Rwandan population were HIV positive and the prevalence of HIV in adults was estimated at 8.9%. The rising number of HIV/Aids cases worldwide has made health care professionals and policy makers search for affordable health care that will meet the needs of those who are suffering from HIV/Aids and enhance their quality of life. The aim of the study was to investigate met and unmet palliative care needs for people living with HIV/Aids (PLWHs) in selected areas in Rwanda. To achieve this aim, the study, firstly, identified the palliative care needs of PLWHs, secondly, it identified the health care services available to meet these needs, and thirdly, it determined the extent to which palliative care needs were met. Both quantitative and qualitative methodologies were used. A sample of 306 participants including 262 PLWHs (250 PLWHs completed questionnaires, 12 PLWHs participated in focus group) and 44 health workers. They included coordinators of HIV/Aids units, medical doctors, nurses, physiotherapists, counsellors, nutritionists and social workers who were purposively selected from two national referral hospitals, one district hospital and three primary health centres. Self-administered structured questionnaires for health workers, structured questionnaires for PLWHs administered with assistance, face-to-face interviews and a focus group were used to collect the data. Given the descriptive nature of the study, both the Statistical Analysis System (SAS) and the Statistical Package for Social Sciences (SPSS) were used to analyse the quantitative data. This was compared and supplemented with qualitative findings using the process of triangulation. Ethical issues pertaining to permission for conducting the study and informed consent were observed. The findings revealed that over 50% of PLWHs had symptoms related to HIV/Aids most of the time with pain as the most common symptom. Furthermore, there was significance between the participants' health status and participation in ADL ($p < 0.001$) patients with no symptoms had a better score in participation of ADL. The most common perceived palliative care needs of PLWHs were control of pain and other symptoms, financial assistance, home-based care, nutritional/food support; access to medical care which included access to ARVs and treatment for opportunistic infections. Despite the health care services and supportive services being available for PLWHs, most of the palliative care needs were still unmet, especially pain and symptom control, financial assistance, nutritional needs and home based care needs.

Despite the information that some participants had benefited from physiotherapy for some of their physical problems, the majority of PLWHs who had physical symptoms had not received physiotherapy. Furthermore, physiotherapy was not yet a part of the palliative care package of care provided to PLWHs in many health facilities. As a result access to physiotherapy was still limited and most of physical symptoms were untreated. Moreover, most of the health workers were not knowledgeable about the role of physiotherapy in palliative care for PLWHs. The majority of PLWHs indicated they would prefer to be looked after at the hospital in the phase of terminal illness. However few of PLWHs reported being visited by a hospital palliative care team. There is a need for improvement of the hospital palliative care service. Incorporation of a comprehensive palliative care program in the continuum of HIV/Aids care and addressing unmet palliative care needs of PLWHs could enhance the quality of life of PLWHs in Rwanda and the health system. The government of Rwanda, in collaboration with national and international funders, needs to focus on strategies of improving the health care provision of PLWHs, especially the palliative care programme. In addition, the development of strategies for poverty alleviation and their implementation are paramount since poverty impedes the health system, especially the HIV/Aids care provision and the well being of PLWHs.



DECLARATION

I hereby declare that: “*Met and unmet palliative care needs for people living with HIV/Aids in selected areas in Rwanda*”, is my own work, that it has not been submitted, or part of it, for any degree or examination in any other University, and that all the resources I have used or quoted have been indicated and acknowledged by means of complete references.

Signature: -----

Jeannine UWIMANA



Witness: -----

Dr. Patricia STRUTHERS

DEDICATION

I dedicate this work to my heavenly father God and my lovely late parents Mukandori, and Aloys .T, to whom I am eternally grateful for their inspiration and motivation in my studies especially in the field of HIV/Aids. Finally, I dedicate this work to all people infected by HIV and orphans of HIV/Aids worldwide.



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MAY GOD BLESS YOU.

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ABBREVIATIONS

| | |
|---------------|--|
| AIDS | Acquired Immune- Deficiency Syndrome |
| ARV | Anti –retroviral drug |
| CHUK | Centre Hospitalier Universitaire de Kigali |
| CHUB | Centre Hospitalier Universitaire de Butare |
| GoR | Government of Rwanda |
| HIV | Human Immunodeficiency Virus |
| MoH | Ministry of Health |
| PLWHs | People living with HIV/Aids |
| QoL | Quality of Life  |
| VCT | Voluntary counselling and HIV testing |
| TRAC | Treatment and Research AIDS centre |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| USAID | The United States Agency for International Development |
| WHO | World Health Organisation |

Terminology

AIDS/Aids: AIDS with upper case is used whenever the organisation listed in the text used it such As TRAC. Aids with a lower case is used within the text when writing up a scientific report as it appears in many scientific reports.

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**MET AND UNMET PALLIATIVE CARE NEEDS FOR PEOPLE LIVING WITH
HIV/AIDS IN SELECTED AREAS IN RWANDA.**

UWIMANA JEANNINE



**Key words: palliative care, needs, people living with HIV/Aids, Adults, terminally ill,
home- based care, physiotherapy, hospital -based palliative care, quality of life, Rwanda.**

CHAPTER ONE

INTRODUCTION

This chapter includes the general overview of HIV/Aids worldwide including the situation in Rwanda, the impact of HIV/Aids on the health system and the efforts made by the government in relation to HIV/Aids treatment and care. The concept of palliative care, its current status in sub-Saharan Africa including Rwanda and the need for palliative care for people living with HIV/Aids are discussed. The overall aim and objectives of the study including the rationale of the study is presented.

1.1. BACKGROUND OF THE STUDY

HIV/Aids is still a threatening pandemic that has eroded many lives and affected the growth and development of many countries, especially in sub-Saharan Africa where the pandemic is increasing and the quality of life (QoL) of people living with HIV/Aids (PLWHs) has been undermined. According to the Joint United Nations Programme on HIV/Aids (UNAIDS) epidemiological report on HIV/Aids in 2003, more than 42 million people worldwide are living with HIV/Aids and more than 28 million have died of the disease. Moreover, the Foundation for Hospice in Africa reports that an unprecedented 30 million people in Africa are living with HIV/Aids, most of them without knowing it (Alexandria, 2003). In Rwanda, the HIV/Aids epidemic has undermined the quality of life of many people who are both infected and affected and furthermore, it has affected all segments of the population, threatening the development and the prosperity of the nation. The UNAIDS epidemiological report (2003), estimates 495,000 PLWHs at the end of 2002 in Rwanda. In addition, the prevalence rates are expected to increase to 691,356 by 2007 (Government of Rwanda & William John Clinton Foundation, 2003). It is against this background of rising numbers that efforts are being made by health care professionals and policy makers to search for accessible health care for those who are suffering from the disease and other equally life-threatening diseases.

An approach that is receiving considerable attention worldwide, especially in sub-Saharan Africa, is palliative care (Abdu-Saad, 2000; WHO, 2002 & Sepulveda, Habiyambere, Amandua, Borok, Kikule, Mudanga, Ngoma, & Bogale, 2003). However, most of the countries in sub-Saharan Africa have not yet incorporated palliative care in their agenda (Sepulveda et al., 2003 & Spence, Merriman and Binagwaho, 2004). It is likely that Rwanda, like any other countries in sub-Saharan Africa, has not yet integrated palliative care into the health system. Hence palliative care needs of PLWHs are still unmet.

1.2. THE PANDEMIC OF HIV/AIDS IN RWANDA

HIV/Aids is a critical problem in Rwanda, as it is through sub-Saharan Africa. HIV infection spread rapidly during the 1994 genocide war due to widespread rape. According to UNAIDS (2001), half of the 3.2% of women in Rwanda who reported being raped during genocide are now HIV positive. By the end of 2002, it was estimated that there were 80,000 new infections with 49,000 deaths attributable to HIV/Aids (UNAIDS, 2003; GoR & William John Clinton Foundation, 2003). Furthermore, the pandemic of HIV/Aids has caused extreme hardship in already impoverished populations. Only 28 % of households with HIV/Aids patients are able to pay for even basic care (USAID, 2004). The 1994 genocide war has also affected the health infrastructure, as most of health facilities were demolished. This affected the health care system in terms of health delivery and access (USAID, 2004). Despite the burden of HIV/Aids on the country, various efforts have been made by the government to fight the pandemic of HIV/Aids and enhance the treatment and care of PLWHs.

1.2.1. Efforts to address HIV/Aids

Like any other country in Sub-Saharan Africa, the Rwandan government has made various attempts to enhance the treatment and care of PLWHs. In June 2003, the Rwandan government approved a five-year HIV/Aids treatment and care plan, which included availability of Anti-retroviral therapy (ART) and other supportive services to PLWHs. With regard to Anti-retroviral therapy (ART), only PLWHs with a CD4 cell counts below $200/\text{mm}^3$ are eligible for ART free of charge. However, treatment for opportunistic infections and other conditions is provided to patients who can contribute almost 10% of the total medical bill (GoR, 2004).

The national system of care and treatment in Rwanda includes Voluntary HIV testing and Counselling (VCT), services coordination, medical treatment including Antiretroviral drugs (ARVs), clinical monitoring and adherence support, psychological care, community and home-

based care (HBC), ancillary support services, as well as prevention and counselling (William John Clinton Foundation, 2003). However, most of the HIV/Aids treatment and care has been delivered in inpatient hospital settings, where supportive care and treatment for opportunistic infections are provided to the extent that resources and drugs are available (GoR & William John Clinton Foundation, 2003). We could thus say that only PLWHs who are living near the hospital setting and able to afford the medical bill can have access to HIV/Aids treatment and care. This suggests that there is still a large number of PLWHs without coverage treatment and care, since most of the patients are poor and live in non-urban areas where most of the well-equipped hospitals are based. This could be associated with limited resources available in the country to cover the needs of PLWHs.

Natasha, Edmond, & Comfort (2002) found that many African countries lack the resources to support an adequate response for meeting the palliative care needs of PLWHs. They recommend that many African countries, including Rwanda, should develop strategies that are cost effective to meet the needs of PLWHs in improving their quality of life.

1.2.2. Impact of HIV/Aids on Health Systems

AIDS affects the economy of Rwanda and the health and welfare of many citizens. According to the Government of Rwanda report (2004), the HIV prevalence in Rwanda is estimated at 13.6% in the general population. With a growing number of PLWHs and needing medical care, the demand for resources is increasing, posing even bigger challenges to the health system. As a result, access to health care is limited, and AIDS-related mortality continues to be a significant phenomenon (Schneider, Nandakumar, Porignon, Bhawalkar, Butera & Barnett, 2000). The constraints of care are not only determined by service delivery, but also by access to health care due to the socio-economic status of PLWHs. Table 1.1 below shows the socio-economic status of people living with HIV/Aids and their access to care in Rwanda:

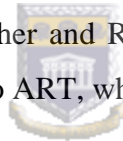
Table 1.1: The socio-economic status of people living with HIV/Aids and access to care

| Group | Socio-economic income group | Number of patients (%) | Treatment received (amount paid by patients) |
|-------|---------------------------------|------------------------|--|
| 1 | High income; Formal sector | 202 (0.05%) | Tri-therapy: \$6,233/patient/year |
| 2 | Middle income; Formal sector | 40,000 (10%) | Opportunistic infections: (care by physicians) \$37/patient/year |
| 3 | Low income; Informal sector | 300,000 (75%) | Opportunistic infections: (care by nurse) \$18/patient/year |
| 4 | Poor; Informal sector | > 50,000 (14%) | Traditional healers: In-kind payments |

The above findings from the Rwandan National Health Accounts reveal that most of the PLWHs belong to the low-income group and that the care cost was \$18 per patient per year. Only a few PLWHs belong to the high-income group and are on Tri-therapy. The annual cost of care using Tri-therapy is estimated at \$6,233 per patient per year. Due to the socio-economic status of PLWHs, the access to care is very limited, and this impacts not only on the quality of life of PLWHs, but also on the health care system.

Concerning the health costs in Rwanda, about 10% of the total per capita health expenditures of US\$12 per person per year is spent on the prevention and treatment of HIV/Aids, and related care (Schneider et al., 2000). In addition, a report from the Ministry of Health on access to anti-retroviral drugs (ARVs) indicates that in 2004, out of 500,000 PLWHs in Rwanda, only 3,524 adults (i.e. above 15 years) and 198 children (below 15 years) living with HIV were on ARVs (TRAC, 2004).

Access and availability of ARVs and other opioid drugs is one of the major critical problems that many African countries face. As Spence et al. (2004) in their article stated that present access to treatment by PLWHs in Africa and Caribbean is essentially controlled by the ability of the patient to pay. Furthermore, Gwyther and Rawlinson (2004) reported in that in South Africa, only 3,9% of PLWHs had access to ART, while 85% had no access.



As the numbers of PLWHs continue to grow and access to treatment and care is limited in Rwanda, the QoL of PLWHs will be compromised if patients' palliative care needs remain unmet. Furthermore, this will lead to a high demand for care, impacting even more seriously on the Rwandan health system (USAID, 2004; Schneider et al., 2000).

The WHO recommends that, in low resource settings where health infrastructure and health care services are limited or poor, there is a need for the integration of palliative care into the health system in order to improve the QoL of PLWHs at all levels of care, by means of services provided mainly by HBC (Sepulveda et al., 2003).

1.3. THE CONCEPT OF PALLIATIVE CARE

Palliative care has many definitions. It has developed and is still growing as a medical specialty, with a longer tradition in some countries than in others (Sepulveda, Marlin, Yoshida & Ulrich, 2002). The World Health Organisation (WHO) defines palliative care as an approach that improves the QoL of patients and their families facing the problems associated with

threatening illnesses such as cancer and HIV/Aids; through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychological, and spiritual (WHO, 2001; WHO, 2002; Singer & Bowman, 2002). The concept of palliative care, especially for PLWHs, is still new in Africa. Most of the health care workers view palliative care as a hospice or end of life care. Therefore, few countries in Sub-Saharan Africa have integrated the new definition or concept of palliative care into their agenda while in sub-Saharan Africa, estimates show that 80% of PLWHs require palliative care (Sepulveda et al., 2002). It is likely that Rwanda has not yet fully integrated the new concept of palliative in its agenda and there is a need for palliative care for PLWHs.

1.3.1 Current status of Palliative care and HIV/Aids in Rwanda

In Rwanda, like many other African countries, the concept of palliative care is still new and its development is still in progress. However, health care and support such as ARVs, VCT and other ancillary support have been provided to PLWHs. As comprehensive treatment programmes, particularly those providing ART, have been limited to several recently initiated pilot programmes, a large number of PLWHs are still in need of care (GoR & William John Clinton Foundation, 2003).



1.3.2. Home-based care for people living with HIV/Aids

Home-based care (HBC) provision in Rwanda started in 2001. However, most of the health facilities do not provide HBC due to various reasons, such as lack of funding and limited human resources, especially health workers (Chandler, Decker & Nzigiye, 2004). However, a few non-governmental organisations such as Family Health International/ IMPACT, AFRICAIRE, WORLD RELIEF, WORLD Vision and others have begun HBC programmes for PLWHs. The Ministry of Health (MoH) has developed guidelines for HBC, but nearly all of the existing programmes are small-scale and relatively new (Chandler et al., 2004). Moreover, several studies have revealed that HBC programme for PLWHs is a promising solution in most of the Sub-Saharan countries (WHO, 2002; Sepulveda et al., 2003).

HBC is considered as an alternative to traditional institutionalised care, and focuses on palliative care within the home. Furthermore, HBC allows for a shorter stay in hospital making more beds available for other patients and reducing costs to the institution (Fox, Fawcett, Kelly & Ntlabati, 2002).

We could therefore say that HBC would be an appropriate palliative care model which could be better developed in countries where health infrastructures are poor, like in the case of Rwanda, where the health infrastructures have been impeded due to 1994 genocide war and where the levels of poverty are high.

The epidemic in Rwanda affects all segments of the population, threatening the development and prosperity of the nation. In the face of the increasing prevalence of HIV, care for PLHWs has changed dramatically in the past decade. Because HIV/Aids is a chronic, progressive disease which may still cause considerable morbidity and mortality, the need for the integration of palliative and curative approaches may be even more important than it was in the pre-Highly Active Anti-Retroviral Therapy (HAART) era (Selwyn & Arnold, cited in Selwyn & Rivard, 2003).

As in other sub-Saharan African countries, the epidemic of HIV/Aids has stretched the already poorly resourced health care infrastructure in Rwanda. The country's per capita income is among the lowest in the world, at \$252, and the GDP is \$7.2 billion. With a growing number of HIV/Aids patients needing medical care and psychological support, the demand for resources is increasing, posing bigger challenges to the health system. The National Health Accounts' findings from 1998 reveal total per capita health expenditures of US\$12 per year. Of these, about 10% was spent on the prevention and treatment of HIV/Aids and related care (Schneider et al., 2000).

Against this backdrop of limited resources and the increasing spread of the HIV/Aids epidemic, there has in recent years been a growing interest in the health care needs of patients (Berk & Nanda, 1997; Berk, Baigis-Smith & Nanda, 1995; Smith & Rapkin, 1995; Hurley & Ungvarski, 1994). Identification and prioritisation of patients' needs can be of assistance in designing appropriate services for HIV patients, especially within the context of financial constraints with regard to health services (Molassiotis, Callaghan, Twinn, & Lam, 2001).

In view of its cost effectiveness and efficiency, the development of palliative care has become necessary to cater for the needs of the sick, as far as improvement in their QoL is concerned (Sepulveda et al., 2002). The WHO recommends this approach to countries with a low resource base as a means of ensuring that palliative care is accessible to all patients and their families in need of this type of care (Sepulveda et al., 2003).

1.4. MOTIVATION FOR THE STUDY

The motivation for this study arose from the researcher's experience in working with adults living with HIV/Aids as a physiotherapist and counsellor in Rwanda. Moreover, due to the fact that, to date, no study has been conducted to identify palliative care needs for PLWHs in Rwanda, it is of great importance to identify palliative care needs for PLWHs as a means of improving health care delivery and improving the QoL of PLWHs.

Since palliative care is multidisciplinary in nature, it involves a team care approach that includes nurses, physiotherapists, medical doctors, counsellors, social workers and religious leaders (Meldbrum, 2003; Addington-Hall & Higginson, 2001). Needless to say, all the main areas of palliative care have implications for physiotherapy. Furthermore, physiotherapy is more than treatment of sports injuries, painful backs, and necks (Glasgow Palliative Care, 2004). Moreover, physiotherapy in palliative care is orientated to achieve the optimum QoL as perceived by patients, since it aims at facilitating the patient's ability to function with safety and independence in the face of diminishing resources (Boyce, 2004).

However, despite the importance of palliative care, its development and acceptance has been rather slow in Africa (Sepulveda et al., 2003). Nevertheless, given the increasing spread of the epidemic on the continent and especially its impact on the Rwandan health system and the development of the country as whole; development of accessible health care that addresses the needs of PLWHs and enhance their QoL, particularly the development of palliative care is imperative. With this in view, the present study is being undertaken to examine met and unmet palliative care needs for PLWHs in selected areas in Rwanda. The focus of this study is based on a description of met and unmet palliative care needs of PLWHs in selected areas in Rwanda, rather than an evaluation study.

1.5. AIM OF THE STUDY

The aim of the present study is to investigate met and unmet palliative care needs for people living with HIV/Aids in selected areas in Rwanda.

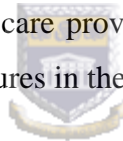
1.6. OBJECTIVES OF THE STUDY

The objectives of the study were threefold:

- To identify palliative care needs of people living with HIV/Aids;
- To identify what health care services are available to meet these needs;
- To determine the extent to which palliative care needs are met.

1.7. RATIONALE FOR THE STUDY

As indicated above, there is a scarcity of data on the palliative care needs of PLWHs on the African continent. This situation is rather unhealthy, since it hampers the efforts to formulate informed policies and programmes that will develop and encourage the use of palliative care to meet the needs of PLWHs. Thus, it is expected that the present study will primarily contribute to the growing body of knowledge about palliative care in Africa as a whole, and Rwanda in particular, and will therefore serve as a need assessment and, a basis for the development of a comprehensive palliative care policy and programmes for PLWHs in Rwanda. In other words, the study is expected to challenge health care providers such as physiotherapists, nurses, and medical doctors to include palliative measures in their care delivery.



1.8. DEFINITIONS OF TERMS USED IN THE THESIS

- **Palliative care:** The WHO defines palliative care as an approach that improves the QoL of patients and their families facing the problems associated with life threatening illnesses such as cancer, HIV/Aids; through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychological, and spiritual (WHO, 2001; WHO, 2002; Singer, 2002).
- **Home-based care:** The World Health Organisation (WHO) defines HBC as the provision of health services by formal and informal caregivers in the home in order to promote, restore, and maintain a person's maximal level of comfort, function and health, including care towards a dignified death (WHO, 2001).
- **Needs:** A common problem in past studies is the lack of definition of the concept need (Molassiotis et al., 2001). Therefore, the conceptualization of need in this study reflects the epidemiological profile of the patients and the areas where assistance could improve the patients' situation or decrease the demand for health care.
- **Palliative care needs:** there are multiple ways of defining palliative care needs based on the definition of palliative care for PLWHs. For this particular study, a palliative care need is not only based on the epidemiological profile of HIV/Aids and the type of group that require palliative care. It also includes the accessibility and availability of health care services, the amount of care already received, and the ability of the patient or other resources to pay for the services (Karus, H.Raveis, Marconi, Hana, Selwyn, Alexander, Perrone and Higginson, 2004).
- **Physiotherapy:** Physiotherapy is a group of services provided by a health care professional that uses specialised physical interventions such as manual therapy, exercise therapy, electrotherapy and other techniques in the management of musculoskeletal, movement, cardio-respiratory and developmental disorders. It can help to restore physical health that has been lost due to injury, disease or other causes. The goals are to relieve pain and promote fitness and health (Campbell, Van der Linden & Palisano, 1994). In addition, physiotherapy in palliative care is orientated to achieve the optimum QoL as perceived by patients, since it aims at facilitating the patient's ability to function with safety and independence in the face of diminishing resources (Boyce, 2004).

- **Quality of life:** The definitions and descriptions of QoL include are both objective and subjective indicators of physical and psychological phenomena (Steenburgen & Rogers in Mutimura, 2001). Objective indicators include income, living situations and physical functioning. On the other hand, subjective evaluations of QoL represent the individual's perception of important life domains and satisfaction with those domains. QoL reflects an individual's sense of well-being and satisfaction with life (Steenburgen & Rogers in Mutimura, 2001). In this study, the focus is based on the Health related quality of life.

1.9. SUMMARY OF CHAPTERS

Chapter one describes the background of the study. The current status of HIV/Aids in Rwanda and the treatment and care for PLWHs, including palliative care, are described. The motivation and the rationale of this study, as well as its objectives, are described.

Chapter two presents the literature review on studies on definitions of palliative care, palliative care and HIV/Aids, while both the met and unmet palliative care needs for PLWHs are presented. Furthermore, it presents various approaches or frameworks used for a needs assessment of palliative care. The literature review provides the background information for this study and the effectiveness of various supports to PLWHs, such as physiotherapy to enhance the QoL of PLWHs.



Chapter three describes the methodology used in this study. The research settings, study design, research subjects and sampling are explained. Furthermore, the chapter describes the study instrument used and the data collection method employed in order to acquire unbiased information. Finally, to conclude this chapter, statistical analysis and ethical considerations are described.

Chapter four presents the results of the study. Perceived palliative care needs for PLWHs and the role of physiotherapy in palliative care are described. Descriptive statistical findings are presented, together with qualitative findings.

In Chapter five, the discussion centres on an attempt to interpret the current study findings, a comparison of the study with similar studies and the impact of the findings. The final chapter, entitled "Summary, Conclusions and Recommendations", serves to summarize the findings, drawing pertinent inferences from the research and proposing suggestions for future action.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter discusses palliative care needs of people living with HIV/Aids among adults, as the majority of those affected happen to be adults, and this constitutes the focus of this study. This chapter provides insight into the most predominant palliative care needs in HIV patients, the preferred place to be looked after in the terminally ill phase, as well as met and unmet palliative care needs. It also discusses the role of physiotherapy in palliative care and suggests how it can enhance the quality of life of PLWHs. Due to the inadequacy of literature on Rwanda, some of the literature reviewed focuses on international studies. The chapter ends with the significance of the use of a corporate need assessment approach for palliative care needs assessment, referring to met and unmet needs that were utilized in this study.

2.2. DATA BASED SEARCH ON PALLIATIVE CARE NEEDS FOR PEOPLE LIVING WITH HIV/AIDS

The literature on palliative care needs for PLWHs studies were obtained by searching the databases summarised in Table 2.1. However, books published from 1990-2005 were also used.

Table 2.1: Summary of Databases and search terms used in the study

| <i>Databases</i> | <i>Search terms</i> |
|-------------------------------------|---|
| Academic Search Premier (1990-2005) | Needs, Home-based care, Hospital based palliative care, Palliative care, Terminal illness, Quality of life, People living with HIV/Aids, Adults, Physiotherapy, and Rwanda. |
| Cinahl (1990-2005) | |
| First search (1990-2005) | |
| Igenta (1990-2005) | |
| Medline (1990-2005) | |
| Science Direct (1990-2005) | |
| Proquest (1990-2005) | |

2.3. DEFINITION OF PALLIATIVE CARE

The definition of palliative care for both cancer and HIV/Aids patients varies in different reports, due to several factors. The main reasons for variations in definition are the evolution of palliative care and the trajectory of the disease, especially for HIV/Aids (Saunders, 2000). The earlier WHO definition of palliative care stressed its relevance to patients not responsive to curative therapy. This statement might be interpreted as relegating palliative care to the last stages of care (Sepulveda et al., 2002).

Today, however, there is a wide recognition that principles of palliative care should be applied as early as possible in the course of any chronic and ultimately fatal illness. These emerge from the understanding that problems at the end of life have their origin in the early stages of the disease. The WHO approach to palliative care has been extended to such an extent that, while pain relief is still an important component, it is by no means the only consideration. The physical, psychological and spiritual needs of the patients are all considered in palliative care. Hence the WHO has reviewed its definition of palliative care and promotes the use of a common definition by health care providers and policy makers in the development of palliative care.



Furthermore, WHO defines palliative care as “an approach that improves the QoL of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002).

The present definition provides comprehensive care, tailored to meet the needs of people experiencing life-threatening illnesses, as well as their families, by improving their QoL. However, the provision of palliative care for people with life threatening diseases by health workers and in health settings, including the evaluation of palliative care programmes, vary in different reports with regard to its definition, while some studies do not state any definition at all. It is therefore important to have a clear understanding of the definition used by the author when comparing results of research studies on palliative care.

Furthermore, a clear understanding of palliative care would help to ensure optimal care by health care providers, since studies have revealed that in many African countries, health care providers lack knowledge and skills about palliative care (Sepulveda, 2004; Gwyther &

Rawlinson, 2004). Table 2.2. serves as summary of different definitions used in studies on palliative care, for both cancer and HIV/Aids patients, published since 1990. Most of the authors (75%) of 15 studies giving definitions of palliative care, used the revised WHO definition.

Table 2.2: Definitions of palliative care according to different authors

| <i>Authors/years</i> | <i>No of studies</i> | <i>Definitions</i> |
|--|----------------------|---|
| WHO, 2001; Jagwe, 2001; Sepulveda et al., 2002; Fox et al., 2002; O'Neill, 2002; Sepulveda et al., 2002; Selwyn et al., 2003; Selwyn et al., 2003; Sepulveda et al., 2003 ; Lancet, 2003; Harding et al., 2003; Meldrum, 2003; Gwyther & Rawlinson, 2004 | 12 | Is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. |
| Foley et al., 1995 | 1 | Is a care for a specific disease, late metastatic cancer, of which the disease trajectory is predictable. |
| Jackie, 2003 | 1 | Is entwinement of treatment and care modalities at all stages of the disease |
| Franks et al., 2000; Kikule, 2003 | 1 | ICare provided as terminal care |

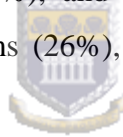
2.4. PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS (PLWHs)

The hospice movement for palliative care was initially developed in response to the perceived need of terminally ill cancer patients, and also because an effective remedy was available but not widely used at the time for pain, patients' most dreaded symptom (Addington-Hall & Higginson, 2001). Furthermore, these authors state that the emergence of HIV/Aids in the 1980s presented a major challenge to this philosophy. There was considerable debate within the hospice movement over the question whether Aids patients would be admitted to hospices.

The needs assessment in the UK on palliative care recognises that cancer patients are not alone in needing palliative care. In addition, the WHO has recommended that palliative care should be provided to all patients with life threatening illness such as cancer and HIV/Aids (WHO, 2002). Furthermore, Sepulveda et al. (2003) state that palliative care should be seen as part of the continuum of care, and not just for patients in the terminal stage of their disease.

Palliative care is globally recognised as a legitimate component of health care. Evidence shows that palliative care is effective in improving the QoL by meeting the needs of people with threatening illness and their families (WHO, 2002; Addington & Higginson, 2001; Sepulveda et al., 2002). In addition, existing data show a considerable symptomatic burden of illness in late-stage HIV disease, suggesting an important ongoing role for palliative medicine interventions (Selwyn & Revard, 2003).

In a study carried out in Canada on the needs of PLWHs and their caregivers, 61% of the respondents with HIV/Aids reported that palliative care would help them throughout their illness. However, other respondents perceived palliative care as an approach to be used in the final stage of illness (Ploem, 2000). In addition, Selwyn and Forstein (2003) in their study conducted in the USA on palliative care for patients with Aids at a large urban teaching hospital, indicate that pain, psychosocial issues, depression, anxiety, nausea/ vomiting, insomnia and family conflicts were problems experienced by PLWHs. However, after the palliative care intervention and follow up, the most successful resolution of problems was seen for psychosocial issues (91%), pain (90%), and nausea/ vomiting (90%). Less successful resolution was seen for memory problems (26%), fatigue/ weakness (66%), and depression (68%).



Although studies have shown evidence of palliative care in improving the QoL of PLWHs by meeting patients' needs, the development of a comprehensive palliative care programme is still slow, while in many African countries government strategies are non-existent (Harding, Stewart, Marconi, O'Neil & Higginson, 2003; Sepulveda et al., 2003). From the above findings, it is likely that Rwanda faces the same problems as any other country in sub-Saharan Africa.

2.4.1. Palliative care initiatives for people living with HIV/Aids in Africa

Palliative care initiatives for PLWHs have recently been developed in Africa. These initiatives have not, however, been well integrated into the country's national health policies, and have therefore not yet had a significant impact on the population of patients needing palliative care. In Africa, 80% of PLWHs need palliative care, but most of the African countries have neglected the integration of palliative care into the health systems (Sepulveda et al., 2002).

The WHO programme on cancer control has developed an initiative to strengthen the development of palliative care in Southern African countries, in collaboration with the WHO departments of Care for HIV/Aids, various governmental and intergovernmental agencies, NGOs, and the WHO Regional Office for Africa (AFRO). Five countries are participating in the project: Ethiopia, Botswana, Uganda, Tanzania and Zimbabwe. The palliative care project started in October 2001. A situation analysis from the five countries reveals a lack of awareness about palliative care in Africa, with the exception of Uganda, that had a government policy on palliative care since 2002 (Sepulveda et al., 2003). The success in Uganda was due to the adoption of palliative care in the national health policy plan. However, Uganda still shares the challenges of unmet needs of PLWHs with other countries due to factors like poverty (Jagwe, 2001; Sepulveda et al., 2003; WHO, 2002).

Moreover, in Africa, palliative care tend to be hospice-linked initiatives that offer excellent care, but do not yet include a public health approach and are not integrated in any health systems (Sepulveda, 2004). The first hospice in sub-Saharan Africa started in Zimbabwe more than 20 years ago, followed by South Africa and the Nairobi Hospice, Kenya in 1990. Hospices have since then multiplied in those two countries. Hospice caring for patients in their homes, by means of 'care team' visits, appears to be the most acceptable, according to the experience of hospice Uganda. This is explained by the fact that cultural context of Uganda revolves around the extended family systems, which makes caring easier (Jagwe, 2001). The cultural context of Uganda revolving around the extended family is similar to many other African countries including Rwanda.

Several studies have shown that HBC is generally the best way of achieving good quality of care and coverage in countries with strong family support and poor health infrastructure (Sepulveda et al., 2002; O'Neill, Romaguera, Parham & Marconi, 2002). However, few studies have evaluated the cost effectiveness of the HBC programme in Africa. Studies that have evaluated the cost of HBC programmes in some other African countries (Zambia and Zimbabwe), have found that the high cost of home visits, especially in rural areas, requires large amounts of resources if frequent home visits are to be offered. Approximately 56-75% of the total cost per home visit was spent on transport costs and time since most of the patients lived in rural areas (Chela, 1995; Hansen, Woelk, Jackson, Kerkhoven, Manjonjori, Maramba, Mutambirwa, Ndimande, & Vera, 1998).

However, Chandler et al. (2004) in their study on estimates cost of providing HBC for HIV/Aids in Rwanda found that facility based care has higher costs per clients than community-based care. Given the above findings, cost for HBC may depend on each country's provision of care and the number of beneficiaries. However, issues of cost effectiveness of HBC remain unproved or controversial, which means that more studies are required in order to shed light on how HBC programmes can best be delivered at low costs, since most of the African countries are poor.

2.5. PREVALENCE OF SYMPTOMS IN PATIENTS WITH HIV/AIDS

Symptoms among PLWHs include a combination of both physical and psychological conditions such as fatigue, anorexia, weight loss and depression. Table 2.3 summarizes the findings of several key studies that have examined the symptom burden in HIV/Aids patients amongst various countries populations. It is striking that these studies, conducted in different countries, showed a remarkable consistency of symptoms across populations even with different selection criteria, over different periods of time, and in applying varying methods for determining the prevalent symptoms. However, pain was the most frequent symptom with an average of 61.6% among PLWHs.



Table 2.3: Prevalence of symptoms in patients with HIV/Aids in different population

| <i>Symptoms</i> | <i>Gwyther & Rawlinson (2004)</i> | <i>Selwyn et al. (2003)</i> | <i>Matthews et al. (2000)</i> | <i>Vogl et al. (1998)</i> | <i>Fantoni et al. (1997)</i> | <i>Kelleher et al. (1997)</i> | <i>Foley (1994)</i> | <i>Larue et al., (1994)</i> | <i>Moss (1990)</i> |
|--------------------------------|---------------------------------------|-----------------------------|-------------------------------|---------------------------|------------------------------|-------------------------------|---------------------|-----------------------------|--------------------|
| | SA | USA | USA | USA | Italy | UK | Canada | France | UK |
| | % | % | % | % | % | % | % | % | % |
| Anxiety / worry | | 19 | | 86 | | | | 40 | |
| Cough | 44,7 | 8 | 30 | | 32 | 19 | 34 | 27 | 30 |
| Constipation | | 9 | | | | 25 | 23 | 2 | 22 |
| Cognitive dysfunction | | | | | | 19 | 43 | | 32 |
| Depression | | 23 | | | | 10 | 32 | 26 | 26 |
| Diarrhoea | 53,4 | | 51 | | 11 | 14 | | 24 | 23 |
| Dry skin | 56,3 | | | | 17 | | 24 | 23 | 27 |
| Dyspnoea/ respiratory symptoms | | 16 | | | 19 | 15 | 48 | 22 | 17 |
| Fatigue | 42,7 | 34 | | 85 | 55 | | 77 | 50 | |
| Fever/ sweats | | 26 | 51 | | | | | 27 | |
| Headache | | | 39 | | | 11 | | | 11 |
| Hemiparesis/ ataxia | | | | | | 23 | | | |
| Loss of appetite | 70,9 | 22 | | | | | | | |
| Low mood/ sadness | 69,9 | 21 | | 82 | | | | 33 | |
| Mouth sores | | 14 | | | | | | | |
| Nausea and vomiting | 44,7 | 10 | 50 | | | | | | |
| Numbness, tingling | | 23 | 49 | | | | | | |
| Pain | 98 | 40 | 71 | 76 | 29 | 55 | 63 | 52 | 71 |
| Incontinence | | | | | | | 55 | | |
| Insomnia | | 13 | | | | | | 37 | |
| Vaginal discharge | | | | | | | | | |
| Visual problems | 81 | | 32 | | 12 | | 25 | | |
| Weight loss | 66 | 13 | 37 | | | | | | |

2.5.1. Pain and symptom management

Since early in the epidemic, several clinical studies have documented a high prevalence of pain and other symptoms in patients with Aids (LaRue & Colleau, 1997; Singer, Fahy-Chandon, Chi, Syndulko & Tourtellotte, 1993; Breitbart, Rosenfeld, Passik, McDonald, Thaler and Portenoy, 1996; O'Neill & Sherrard, 1993; Norval, 2004; Gwyther & Rawlinson, 2004). However, several studies have revealed pain to be the most common symptom experienced by PLWHs and likely to be under-diagnosed and under-treated (Breitbart et al., 1996; O'Neill & Sherrard, 1993; Gwyther & Rawlinson, 2004).

Norval's (2004) study on the prevalence of symptoms in HIV patients, in particular, comments that international studies have shown that 80% of HIV patients experienced inadequate pain management. Studies have shown that inadequate pain management is due to lack of knowledge on HIV/Aids, palliative care and pain control, as well as lack of access to essential analgesics or ARVs (Gwyther & Rawlinson, 2004; O'Neill et al., 2002). The study of O'Neill et al. (2002) on current HIV/Aids end-of-life in sub-Saharan Africa, which evaluated 14 countries including South-Africa, Zambia, Tanzania, Zimbabwe, Uganda, Benin, Ethiopia, Gambia, The Ivory Coast, Malawi, Nigeria, Sierra Leone and Swaziland, reveals that 94% of health providers reported challenges in pain control (including availability of drugs, lack of trained providers, stigma and legal restriction).

To date no published study in Rwanda has assessed pain control and symptoms management among PLWHs. However, it is probable that the above findings reflect the situation in Rwanda. Authorities indicate that any investment in palliative care would be at the expense of providing life-saving treatments for those suffering from curable, often infectious illness (Spence et al., 2004). This suggests that that pain relief and symptom management may be amongst the unmet palliative care needs for PLWHs in Rwanda as well as in most other African countries.

Gwyther and Rawlinson (2004) analysed the site of pain and found that the most common site of pain was lower limbs (66%). This pain is most likely the result of a peripheral sensory neuropathy related to HIV. Selwyn & Rivard (2003) said that pain and symptom management have also grown with several factors, including drug toxicities and symptomatic sequelae that occur in patients on long-term antiretroviral therapy.

Pain management is a critical component of palliative care for improving the QoL of PLWHs, yet few countries worldwide have managed to improve pain management. Africa still faces great challenges in the management of pain and other symptoms, due to several factors, which include availability and access to drugs, including ARVs and opioids. Few health workers are able to prescribe appropriate drugs (WHO, 2002).

A comprehensive palliative care approach is needed that includes not only ART, but also complementary therapies such as physiotherapy interventions in the management of neuromuscular pain, since despite the toxicity of ART causing pain, the most common source of the pain in Aids patients is peripheral sensory neuropathy related to HIV (Gwyther & Rawlinson, 2004).

2.6. PALLIATIVE CARE PROGRAMME/SERVICES

Generally, the palliative care programme in most of the countries provide the following services:

- Medical care, which includes pain and symptom management as well as ARVs and opioid drugs.
- Psychosocial support that includes emotional or psychological support for both patients and their families.
- Bereavement support (Harding and Higginson, 2001).



Although the definition of palliative care is globally relevant, whatever constitutes palliative care needs and services in sub-Saharan Africa is continent-specific, particularly in the light of the extent of poverty and HIV disease (Harding & Higginson, 2004). Necessary components include practical care; pain and symptoms control; counseling/emotional/psychological support; income generation; financial support for food; shelter; funeral costs and school fees; respite; spiritual support and orphan care (Harding & Higginson, 2004; Coughlan, 2004). This suggests that palliative care in sub-Saharan Africa should incorporate the above-mentioned services for the programme to be effective and meet the needs of PLWHs.

The main places for palliative care for PLWHs include hospitals, hospices and homes. Palliative care for PLWHs in tertiary hospitals focuses mainly on pain and symptom management, although they admit that the need to address social, emotional, psychological and spiritual care is urgent.

However, resources are scarce in many African countries where palliative care services are in existence and they are often unable to employ multidisciplinary teams (Coughlan, 2004). In addition, Coughlan's (2004) study found that teams that exist in tertiary settings comprise mainly nurses and doctors aiming to fulfill multiple roles.

In addition, several studies have shown most of the PLWHs prefer to be looked after at home (Kikule, 2003; Sepulveda et al., 2003). However, in some countries, such as Ethiopia 58% of PLWHs would rather be cared for in hospital (WHO, 2002). Hence, the type of care that could be referred to as hospital-based palliative care could be improved to meet the needs of PLWHs who prefer hospital care. Given the differences from countries on preferred place to be looked after in terminal illness, this suggests that the provision of palliative care at the end- of life of PLWHs should be based on the social-cultural context of each country.

2.7. PALLIATIVE CARE NEEDS OF PEOPLE LIVING WITH HIV/AIDS

The trajectory of HIV/Aids has changed, and the need for palliative care is a pressing issue for PLWHs. However, the needs of PLWHs vary depending on the stage of the illness. In Hurley and Ungvarski's study of 1994, key findings suggest that the health care needs of PLWHs extend beyond the clinical manifestation of the disease. These include physical problems (pain, fatigue, and others), inadequate nutrition and compliance with medication, inadequate home facilities, financial concerns and lifestyle concerns. Based on the WHO on palliative care, the above-mentioned constitute palliative care needs. Table 2.4. summarizes the prevalence of palliative care needs in HIV/Aids patients. The most frequent needs are: financial (18,4%), access to medical care (11,5%) and spiritual (9,8%), while food and pain relief and other symptoms showed the same average (7,8%).

Table 2.4: The frequency of palliative care needs of people living with HIV/Aids (n=16)

| Expressed needs | <i>Karus et al. (2004)</i> | | | <i>Lau et al. (2003)</i> | <i>Rani et al. (1997)</i> | <i>WHO (2002)</i> | | |
|---|----------------------------|-----------------|----------------|--------------------------|---------------------------|-------------------|--------|----------|
| | Alabama (USA) | Baltimore (USA) | New York (USA) | China | USA | Ethiopia | Uganda | Tanzania |
| | % | % | % | % | % | % | % | % |
| Pain relief and other symptoms | | | | | | 76 | 41 | |
| *Psychological support | | | | 37,6 | | 20 | | 14,5 |
| Access to medical care | | | | 86,3 | 85,5 | | | |
| **Financial assistance | 29 | 37 | 8 | 39,9 | 55,5 | 50 | | 62,5 |
| Stigma and discrimination | | | | 24 | | | | 90 |
| ***Food provision | 10 | 26 | 13 | | 57,2 | | 23 | |
| Spiritual support | 7 | 91 | 22 | | | | | 47,5 |
| Housing/ Shelter | 17 | 29 | 24 | | | | | |
| Nutritional counselling | 42 | 52 | 41 | | | | | |
| AIDS related info | | | | 64,5 | | | | |
| Mental care | | | | | 69,7 | | | |
| Dental care | | | | | 70,2 | | | |
| Home care | | | | 18,2 | | | | |
| Inpatient care | | | | 18,4 | | | | |
| Physical, occupation and rehabilitation | 2 | 42 | 34 | 38 | | | | |
| Legal services | 5 | 13 | 11 | | | | | |

*Psychological support includes counselling for both patient and family

**Financial assistance includes living expenses, school fees for children, transportation, etc

***Food provision includes provision for both patient and family

Palliative care needs for PLWHs are multifaceted, depending on many factors such as the stage of the disease, the health infrastructure or system of each country and the socio-economic status of PLWHs. However, most of qualitative and quantitative studies show that pain relief and symptom management, psychological support, spiritual support, food and financial support are the most predominant palliative care needs for PLWHs in many countries across the globe (Beedham & Wilson-Barnett, 1995; Grant, Murray, Grant & Brown, 2003; Harding et al., 2003; Harding & Higginson, 2004; Karus et al., 2004; Kikule, 2003; Lau, Tsui, Li, Chung, Chain & Mollasiotis, 2003; Lasechinger, Van Manen, Stevenson & Fothergill-Bourbonnais, 2005; Sepulveda et al., 2003; Spence et al., 2005; Rani, Mitchell, Mini-Sun & Jan., 1997; WHO, 2002). In developed countries such as USA, needs for legal services, nutritional counselling, HIV/Aids information and physiotherapy, occupational therapy and rehabilitation were expressed more often than in African countries. Based on the studies mentioned above, an overview of issues and challenges related to the most predominant areas of palliative care needs in HIV/Aids patients are highlighted in section **2.7.1 –2.7.5**.

2.7.1. Medical care access

In Uganda, the senior advisor on national policy and advocacy on pain control at Hospice Uganda reported that 57% of Ugandan people who are HIV positive could not access health care or services (Jagwe, 2002). Several studies have shown that internationally, in resource-poor settings, especially African countries, there may be no access to ARVs or no access to care in a very late stage of the disease (O'Neil et al., 2002; Sepulveda et al., 2002; WHO, 2002; Harding et al., 2003; Spence et al., 2004).

In South Africa, Gwyther and Rawlinson (2004) found that only four patients (3.9%) had access to ART, while the remainder had no access to ART. In Rwanda, out of 84,000 persons who are estimated to be symptomatic and requiring ARVs, only 1% of PLWHs were receiving treatment (GoR & William John Clinton Foundation, 2003). This suggests that access to medical care in many African countries is limited. The main factor causing the limitation of access to medical care is poverty (Harding et al., 2003 & Sepulveda et al., 2003).

2.7.2. Psychological support

Harding and Higginson's (2004) report on palliative care in sub-Saharan Africa stated that PLWHs and their families need emotional and psychological support, but psychological needs are rarely identified. Few such interventions for sub-Saharan African clients have been described. Palliative care services must address the psychological problems associated with the disease process, not only in the patients, but also in the family units supporting the patients (Franks, Salisbury, Bosanquet, Wilkinson, Kite, Naysmith, Higginson, 2000).

It is well documented in the literature that depression and anxiety are common among PLWHs and several studies have shown the unmet need of emotional or psychological support for PLWHs (Moss, 1990; La rue et al., 1994; Selwyn et al., 2003; Kikule, 2003; Sepulveda et al., 2003). However, little conclusive information exists as to which psychologic intervention could decrease psychological distress in PLWHs.

A study on the effects of Cognitive Behavioural Group Therapy (CBT) and Peer Support/Counselling (PSC) in decreasing psychological distress and improving QoL in Chinese patients with symptomatic HIV disease revealed that 34% patients with psychological conditions who received the intervention (CBT and PSC) improved significantly in psychological functions in terms of depression, fatigue, mood disturbance, anxiety and anger (Molassiotis et al., 2002). Therefore we could say that health care providers in palliative care could use the CBT and PSC for PLWHs as a psychological intervention/support.

2.7.3. Nutritional support

Nutritional support in HIV patients is also one of the needs that need to be addressed. The interaction between HIV/Aids and nutrition has particular significance because malnutrition and infectious or communicable diseases such as tuberculosis, malaria and leishmaniasis are common in sub-Saharan Africa. These conditions may occur simultaneously, sequentially or repeatedly in HIV infected people (Anabwani & Navario, 2005). Studies have also shown that micronutrient deficiencies are common in PLWHs and may accelerate progression of HIV disease, which in turns leads to worsened nutritional status (Skurnick, Bogden & Baker, 1996; Ullrich et al., 1994; John, Ndati & Mbori-Ngacha, 1997; Normen, Chan, Braitstein, Anema, Bondy, Montaner & Hogg, 2005).

A study carried out in British Columbia, Canada, on food insecurity and hunger prevalence among PLWHs showed that the occurrence of food insecurity or lack of food was nearly five times higher than in the general Canadian population (Normen et al., 2005).

Estimates from food relief groups in Rwanda suggest that approximately 50% of PLWHs required some form of food assistance. Only 20% of the need for food assistance was met (USAID, 2004). Therefore, food support to PLWHs is paramount to improve the condition of PLWHs.

2.7.4. Financial support

It is well known that poverty affects sub-Saharan African countries and that the effects of poverty leads to poor health infrastructure and ill health, especially in PLWHs where the trajectory of the disease has changed since the introduction of Highly Active Anti-Retroviral Therapy (HAART). This has become a chronic disease dependent on the person's income. The illness of a breadwinner in many African countries is devastating for their families (Selwyn & Forstein, 2003; USAID, 2004).

HIV/ Aids will result in a loss of income for PLWHs, and a switch of household expenditures to health care costs, as well as funeral and mourning costs (USAID, 2004). In addition, a study on household expenditure by PLWHs in Rwanda showed that HIV seriously impairs the ability of the households to meet basic needs (Schneider et al., 2000). Spence et al. (2004) reported that access to treatment was essentially controlled by the ability of the patient to pay. Furthermore, Saver and Peterfreund's (1993) study showed that poor individuals were likely to lack regular sources of care due to financial reasons. Hence financial support is required in order to enable PLWHs to meet their needs like medical care access, food and others.

2.7.5. Home-based care

Home-based care (HBC) is by far the most common model of palliative care provision in Africa. It is a resource-led decision in response to high numbers of patients and modest resources, thereby maximizing coverage and sustainability.

HBC offers flexibility and an increased potential for culturally appropriate care, but is limited by the suitability and availability of a home and family care network, and by the geographic area that can be feasibly covered by palliative care providers (Harding & Higginson, 2004).

This is supported by the study of Hansen et al. (1998) on the cost effectiveness of HBC for PLWHs in Zimbabwe. The findings showed that 15-33% of HIV/Aids patients in Zimbabwe needed HBC, but the coverage was only 2-4%. In Rwanda, the existing programmes on HBC are small-scale and relatively new, hence the need for HBC for PLWHs is still unmet (Chandler et al., 2004).

In conclusion, the literature has highlighted the level of need for palliative care and the disparity in palliative care provision. This is supported by Harding et al. (2005) in a study on access and equity in HIV/Aids palliative care. The findings show that although there is evidence for both needs and effectiveness of palliative care in HIV patients, access to palliative care is often poor and the care is less than optimal. Although there is evidence of palliative care needs for PLWHs, few studies have assessed to what extent needs are met, while the assessment of both met and unmet needs is crucial for effective health service planning (Willes, Payne and Jarrett, 1999).

Most of the studies that have assessed both met and unmet needs are qualitative in character. Their findings reveal that pain relief and symptom management, psychological support, training of family caregivers, financial assistance, food provision, home care, in patient care, Aids information, housing, dental care and dealing with stigma and discrimination, are amongst the most common unmet needs. In a minority of cases needs are met mainly through the families and relatives (Beedham & Wilson-Barnett, 1995; WHO, 2002; Sepulveda et al., 2003; Lasechinger et al., 2005). In addition, studies conducted in Ontario (Canada) by Williams (1999), The Ivory Coast by Coughlan (2004) and by WHO (2002) on the five countries which are part of the project on palliative care in Africa, identify challenges for health care providers to supply optimal palliative care. These challenges relate to: lack of trained human resources; lack of understanding of palliative care among health providers; high shortage of health professionals and social workers; inadequate number of hospices and day care centres; inadequate regulatory frameworks; inadequate funds for activities; lack of training for HBC providers; lack of building and space; lack of multidisciplinary teamwork in palliative care; inadequate treatment modalities for pain and other symptoms and lack of national strategy on palliative care. This suggests that the above-mentioned challenges may be similar to that of Rwanda regarding the provision of optimal palliative care.

2.8. PREFERRED PLACE TO BE LOOKED AFTER BY PEOPLE LIVING WITH HIV/AIDS IN TERMINAL ILL PHASE

A report on the New Zealand palliative care strategy (2001) revealed that according research, 50-70% of people with threatening illnesses such as cancer and HIV/Aids would prefer to have the choice of home care. In addition, several studies in sub-Saharan Africa have revealed the need of PLWHs to be looked after at home in the terminally ill phase (Kikule, 2003; WHO, 2002, Sepulveda et al., 2003; Spence et al., 2004). However, HBC reaches a small number of people in need (Hansel et al., 1998; Harding & Higginson, 2004). Based on the above findings on HBC, there is evidence of a need for a large-scale strategy for HBC. It is of great importance to meet the needs of the patients at the end of their lives, helping them to die in dignity in the presence of their families.

2.9. PHYSIOTHERAPY AND PALLIATIVE CARE

Palliative care is multidisciplinary in nature; it involves a team care approach that includes nurses, physiotherapists, medical doctors, counsellors, social workers and religious leaders (Meldbrum, 2003; Addington-Hall & Higginson, 2001). Needless to say, all the main areas of palliative care have implications for physiotherapy. Physiotherapy amounts to more than the treatment of sports injuries, painful backs and necks (Glasgow Palliative Care, 2004). Moreover, physiotherapy in palliative care is orientated to achieve the optimum QoL as perceived by patients, since it aims at facilitating the patient's ability to function with safety and independence in the face of diminishing resources (Boyce, 2004).

Studies have shown that many drugs used to treat opportunistic infections interact negatively with ARV drugs. Peripheral neuropathy is one of the major toxicities and complications of ARVs. This may affect the issue of adherence, a major determinant of successful therapy (Anabwani & Navario, 2005; Selwyn et al., 2003). Therefore, neuropathic pain should be well managed by including non-opioid drugs and physiotherapy.

Furthermore, Simpson & Tanglia in Salati (2004) reported that 50% of HIV patients end up with neurological complications. As the HIV virus spreads, the role of physiotherapy will increase because of the neurological and non-neurological complications associated with infections (Salati, 2004).

Few conclusions have been arrived at as to the role of physiotherapy in palliative care for PLWHs and the effectiveness of physiotherapy interventions. However, massage therapy and exercise therapy has been proven to be effective in PLWHs (Diego, Field, Hernandez-Reif, Shaw, Friedman & Ironson, 2001; Birk, McGrady, MacArthur & Khuder, 2000).

2.10. CONCEPTUAL APPROACH FOR PALLIATIVE CARE NEEDS ASSESSMENT

The definition of palliative care has been used differently in past studies (Franks et al., 2000; Molassiotis et al., 2001; Kikule, 2003; Sepulveda et al., 2003). This has led to different approaches in conducting palliative care needs assessments for PLWHs and interpreting the results. A narrow conceptualisation of needs may not reveal all the demands of the illness trajectory placed on PLWHs (Molassiotis et al., 2001). Various approaches to palliative care needs assessment have been used in past studies. These includes: the epidemiological approach, which focuses on the cause-specific mortalities in diseases likely to benefit from palliative care; the alternative approach distinguished need, demand and supply; the normative approach which is based on identification of needs and efficacious treatment; and the corporate approach seeking the views of patients' carers on the perceived needs and the extent to which needs are met. Table 2.5. illustrates different approaches or conceptual frameworks related to the research design used for a palliative care needs assessment.

Table 2.5: Needs assessment approaches used in palliative care

| <i>Authors/years</i> | <i>Conceptual framework/ approach</i> | <i>Definitions</i> | <i>Research method</i> |
|--|---------------------------------------|--|--|
| Conway et al., 1995; Wiles et al., 1999 | The corporate Approach | Is an approach that identifies provider agencies providing care for patients with a terminal illness and their carers in the area, and identifies the range of services provided. It also seeks the views of patients and carers on the perceived palliative care needs, and the extent to which needs are met. It also includes the stakeholders involved in palliative care services, views on perceived inadequacies and gaps in services. | Triangulation method (Quantitative and Qualitative) |
| Karus et al., 2004 | Normative Approach | Is an approach that assumes that a need occurs when a client's functioning is threatened by a remediable cause. It is based on identification of needs, efficacious treatment or services available | Quantitative method |
| Stevens and Gabbay, 1991; Karus et al.,2004 | Alternative Approach | It is a framework that distinguishes needs (services that would benefit the patient), demand (services that patients or providers request), and supply (services that are available and provided to patients). | Quantitative method |
| Franks et al., 2000; Addington-Hall & Higginson, 2001 | Epidemiological Approach | It is based on the cause-specific mortalities in disease likely to benefit from palliative care, and then relates this to the type and frequency of symptoms experienced by patients suffering from terminal stages of the disease. | Quantitative |

Much of the research in the HIV/Aids field has focused on epidemiology, pathology and medical complications using the epidemiological approach (Beedham & Wilson-Barnett, 1995). This method is useful in identifying all palliative care needs (Franks et al., 2000).

Based on the revised WHO definition on palliative care for cancer and HIV/Aids, none of these approaches illustrated in table 2.4 have not included patients at all stages. Little systematic effort is being made to assess the needs of the client group at earlier stages, particularly from the perspective of health care providers and stakeholders, clients (patients and their families). Franks et al. (2000) pointed out that to complete the whole picture of palliative care needs, one should not only evaluate the unmet needs of the users of specific services, but also attempt to find patients who are not receiving care who would benefit from the services on offer. Therefore, I suggest that the corporate and the epidemiological need assessment approaches are combined, as they could give a comprehensive picture on the palliative care needs of PLWHs based on all stages of the disease.

However, the 1994 genocide war in Rwanda resulted in a poor health infrastructure with poor data collection and health information. Systematic data on symptoms among HIV patients is lacking. Hence, the use of a combined epidemiological and corporate approach is impracticable, because an epidemiological approach relies on accurate data. Within this study the needs assessment framework used was based on corporate approach from the perspective of the revised WHO definition on palliative care for Cancer and HIV/Aids.



2.11. SUMMARY

All over the world the burden of HIV/Aids is overwhelming especially so in sub-Saharan Africa where the prevalence of HIV/Aids is higher than elsewhere in the world, and combined with a higher rate of Aids related deaths (UNAIDS, 2004). The most prevalent symptom in HIV patients is pain, yet pain management is inadequate in many African countries. The most common source of pain in HIV patients is pain in the lower limbs due to peripheral neuropathy. This is caused by the toxicities and complications of ARVs and other drugs used for treatment of opportunistic infections (Selwyn et al., 2003; Gwyther & Rawlinson, 2004). Physiotherapy interventions such as massage and exercise therapy have been found to be effective in palliative care by improving the QoL of PLWHs (Birk et al., 2000; Diego et al., 2001).

With regard to HBC in sub-Saharan-Africa, HBC is the common model for palliative care. However, its cost effectiveness is still questionable. Palliative care needs of PLWHs are multifaceted.

However, pain relief and symptom management, financial support, food, housing, spiritual support, psychological support for both patients and their families and access to medical care are real needs in PLWHs. Where needs are met, it is mostly through the family and relatives of the patients (WHO, 2002).

Unmet palliative care needs are related to various factors such as poor health infrastructure, poor management of pain and symptoms, lack of trained health professionals in palliative care, lack of government strategies or policy and poverty (WHO, 2002; Sepulveda et al., 2003; Harding & Higginson, 2004; WHO, 2004). It is likely that the palliative care needs of PLWHs in sub-Saharan countries are similar to Rwandan PLWHs, although no study has been yet conducted. Therefore, prior to development and planning of palliative care programmes for PLWHs, a needs assessment is paramount. The approach adopted in this study is based on the corporate needs assessment model, which provides a comprehensive picture on met and unmet palliative care needs. The following chapter will discuss the methodology used in this study.



CHAPTER THREE

METHODOLOGY

3.1. INTRODUCTION

This chapter describes the method utilized in the study. Included in the chapter are descriptions of the research settings, the study sample and study designs. A description of pilot studies is given, as well as an explanation of how data analysis was carried out. Finally, the issues of ethical consideration related to the study are described.

3.2. RESEARCH SETTING

The research setting included two national referral hospitals from Rwanda, one district hospital, two health centres and a day clinic from the Treatment and Research AIDS Centre (TRAC). These health facilities were chosen, because they are sites for HIV/Aids care and Anti-retroviral therapy (ART) and have palliative care programmes. In addition, these health facilities have a high number of adults living with HIV/Aids.

The study was carried out at two referral hospitals, which are:

Centre Hospitalier Universitaire de Kigali (CHUK) and Centre Hospitalier Universitaire de Butare (CHUB) and one district hospital namely Hôpital de district de Kabutare. The health centres included were Health Centre of Kicukiro-PMTCT, and the Psychosocial Health Centre of Biryogo. A map of Rwanda that illustrates the location of provinces where the study was conducted is provided (Appendix L).

3.2.1. Centre Hospitalier Universitaire de Kigali (CHUK)

Centre hospitalier Universitaire de Kigali is situated in Kigali province in the centre of Kigali, the capital city of Rwanda. It is a university teaching and a national referral hospital to which most people from remote rural areas are referred for the treatment or rehabilitation of various health conditions. It has the largest internal medicine wards which accommodate a large number of adults living with HIV/Aids, and has an HIV/Aids care unit where most patients from various provinces around the country are referred to for further treatment and care, including palliative care. It has a well-equipped physiotherapy department.

3.2.2. Centre Hospitalier Universitaire de Butare (CHUB)

Centre hospitalier Universitaire de Butare is situated in the Butare Province in the centre of Butare province, the second largest province in Rwanda. It is also a university teaching and a national referral hospital for patients with various health conditions from other provinces in the south - western part of the country where patients are referred for treatment or rehabilitation. The Faculty of Medicine of the Rwanda National University is attached to this hospital and it has a renovated and well-equipped Unit for HIV/Aids care. It is the first referral hospital in Rwanda to have an HIV/Aids care unit with a HBC programme.

3.2.3. District Hospital of Kabutare

The district hospital of Kabutare is situated in the Butare Province in the district of Ngoma. It is one of the provincial hospitals with a large number of patients living with HIV/Aids, especially those who come from the remote rural areas and it is the only provincial hospital in the country that has a HBC programme which accommodates more than 200 patients on its programme of ART and food provision.

3.2.3. Health Centre of Kicukiro



Health centre of Kicukiro is situated in the Kigali Province, about 15 km from the town of Kigali. It is similar to other primary health care centres, but it is one of the health centres used to pilot the Prevention to Mother to Child transmission (PMTCT) initiated by Bill Clinton, the former president of the USA. Most of the pregnant mothers who are HIV positive from Kigali province are referred to this centre where treatment for the family is provided at a lower cost compared to other health centres in the country. It also has a new and well-equipped HIV/Aids care unit that has a HBC programme.

3.2.4. Psycho-Social Health Centre of Biryogo

The Psycho-Social Health Centre of Biryogo is situated in the Kigali Province, about 25 km away from the town, in one of the suburbs named Biryogo. Initially this centre started as a private health centre that catered for the poorest (indigent) people living in that area. The importance of the centre was to cater for the psychosocial needs of indigent people.

At present, the centre is affiliated with national health centres and the target group for the HIV/Aids unit care is commercial sex workers and the poorest people living in the vicinity. It also provides palliative care with nutritional support to PLWHs.

3.2.5. Treatment and Research AIDS centre (TRAC)

The Treatment and Research AIDS Centre (TRAC) is situated in the city of Kigali Province, and it is a day clinic which provides palliative day care. This big and well-equipped clinic has a unit that provides ART to most of the PLWHs from across the country and treats opportunistic infections. It has the largest voluntary counselling and testing unit. The day clinic is attached to the Centre Hospitalier Universitaire de Kigali (CHUK) where patients are admitted and provided with HBC. It is also the national organisation in charge of HIV/Aids care, treatment and AIDS research.

3.3. STUDY DESIGN

Both descriptive quantitative and qualitative analytic designs were used in the study. The use of multiple methods is called triangulation. De Vos (2001) stated that triangulation is used with a view to increase reliability. Furthermore, the triangulation method makes the study findings more informative and comprehensive. Therefore, apart from quantitative methodology, the informants' qualitative points of views were obtained using individual interviews and a focus group with an interview guide, while questionnaires were used in the quantitative research.

Face to face interviews with a structured questionnaire for HIV/Aids patients were used in the qualitative research. They received assistance, as they were too ill to complete the questionnaire on their own. Health care workers used a self-administered questionnaire. Qualitative research was utilised in order to determine the participants' true perceptives of their met and unmet palliative care needs. This combination of methods provided a valid reflection of the participants' perceived palliative care needs and their own experience with HIV/Aids care, instead of using either quantitative or qualitative methods alone.

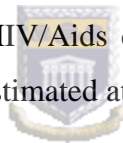
3.4. STUDY POPULATION AND SAMPLING

The study population included all adults from the age of 15- over 60 years who were diagnosed as HIV positive, as well as health workers involved in HIV/Aids care who voluntarily agreed to participate in the study. The study sample included two hundred and fifty adults living with HIV/Aids and 50 purposively selected health care workers.

Twelve PLWHs members of one of the associations of PLWHs affiliated with the national association of PLWHs (ANSP+), were purposively selected and were included in a focus group discussion. Four coordinators of HIV/Aids units from health facilities involved in the study were also purposively selected for interviews.

A purposive sampling method was used in order to gather in-depth information from the key informants who had an overview on palliative care of PLWHs and to obtain an understanding of feelings and perceptions from PLWHs (beneficiaries) and health providers (coordinators). According to Armitage & Berry (1996) and Bless & Higgson-Smith (2000), purposive sampling is used in special situations in which a researcher selects unique cases that are especially informative for in-depth investigations.

Inclusion criteria included individuals' seropositive who could read and write, and those with the cognitive ability to comprehend and communicate. Exclusion criteria were individuals under the age of 15 years or over the age of 60 years, those with severe cognitive problems and those with disabilities such as blindness or deafness. The choice of this particular age group is due to the high prevalence of HIV/Aids in this population. According to UNAIDS (2003) and the Rwandan National Commission on HIV/Aids control (CNLS) reports, the prevalence of HIV/Aids among adults (15-49 years) is estimated at 8,9%.



Health workers included in the study, were physiotherapists, nurses, medical doctors, counsellors or psychologists, social workers, nutritionists who were part of the palliative care team or had been involved in HIV/Aids care for more than one year in the selected health facilities. The coordinators of HIV/Aids units are people who oversee HIV/Aids care programmes at health facilities. The total sample size of this study was 306.

3.5. METHODS OF DATA COLLECTION

This study utilized two methods of data collection, namely quantitative and qualitative.

3.5.1. Quantitative method

The quantitative part of the research comprised a questionnaire for PLWHs adapted from the literature (Steward et al., 2000; Kikule, 2003). Items adapted included identification of symptoms including physical symptoms; physiotherapy treatment; monthly income and medical expenditure [Rwandan currency: Frw] (Appendix A). The questionnaire for health workers was adapted from Steward et al. (2000).

Items adapted included services provided to family members of PLWHs, resources needed to meet palliative care, training related to HIV/Aids and palliative care and the role of physiotherapy in palliative care (Appendix B).

3.5.1.1. Questionnaire for People Living With HIV/Aids

Section A included demographic characteristics, age, gender, level of education, occupation and place of domicile.

Section B included HIV-related information, the care provided and identification of needs, HIV status, other HIV related information such as illness/conditions experienced; and care provided; and identified palliative care needs.

Section C included support given to PLWHs such as ARVs and home visits, and home- based care and hospital-based palliative care.

3.5.1.2. Questionnaire for Health Workers

Section A included personal information such as age, gender, level of education and qualification.

Section B included information on, firstly, health care/services provided to PLWHs and their families and, secondly, their perception of palliative care needs they thought PLWHs experienced.

Section C included the level of knowledge on HIV/Aids and palliative care, and the role of physiotherapy in palliative care for PLWHs.

3.5.2. Translation

Prior to the fieldwork, two professional translators, one French and the other Kinyarwanda, translated the questionnaire from English to French and Kinyarwanda (Appendixes C & D). The questionnaire was translated from English to French for health workers who did not understand English and spoke French (Appendix D). The questionnaires for PLWHs were translated from English to Kinyarwanda, since the majority of HIV/Aids patients speak Kinyarwanda (Appendix C).

3.5.3. Qualitative Method

For the qualitative component of the study, guided, in-depth, individual interviews were carried out with stakeholders involved in HIV/Aids care, including palliative care.

A focus group with 12 PLWHs selected members of an HIV/Aids association namely “TWISUGANE” which means let us come together, was also carried out. The “TWISUGANE” association is an association of PLWHs with a membership of more than 200 members. The researcher developed interview guides (Appendixes E & F) used for individual interviews and focus groups. The interview guide included issues the researcher found needed more in-depth information to supplement the information provided by questionnaires. It was developed after the questionnaires had been administered.

3.6. RELIABILITY AND VALIDITY OF THE QUESTIONNAIRE

Validity is an indication of the extent to which an instrument measures what we think it is supposed to be measuring (Sarantakos, 1998). Hence, the verification of the translated questionnaires was done to ensure the validity of the instruments and questionnaires were also piloted to establish content and face validity.

Reliability refers to dependability or consistency of the measurements (Sarantakos, 1998). By utilising both quantitative and qualitative methods simultaneously, the results were more reliable than if one method was used alone. Furthermore, Neuman (2000) indicated that integrating the two methods provides a general picture of the problem.

Qualitative research may facilitate the interpretation of relationships between variables, whereas quantitative research readily allows research to examine relationships among variables, but is often weak when it comes to exploring the reasons for those relationships (Punch, 1998). In addition, triangulation reduces also the possibility of bias and produces results that are more reliable with complimentary strengths (Rees and Bath, 2001).

3.7. CREDIBILITY AND TRUSTWORTHINESS

To enhance credibility and trustworthiness of the qualitative study, the following procedures were followed:

Firstly, the involvement of people living with HIV/Aids from an association of PLWHs, HIV/Aids patients who are hospitalised and outpatients, health workers involved in HIV/Aids care, together with coordinators of HIV/Aids care unit. Their involvement provided a general picture and an understanding on palliative care needs of PLWHs from different sources, thus helping to avoid biases.

De Vos (2002) stated that data/findings from different sources could be used to collaborate, elaborate or illuminate the research in question. Designing a study in which multiple informants are used, can also greatly strengthen the study's usefulness for other settings.

Secondly, the language used for focus-group discussions and individual interviews matters in terms of credibility and trustworthiness of a study. The use of Kinyarwanda, French and English allowed the researcher and the participants to communicate clearly and easily, since participants were more conversant in those languages. The interviewer was fluent in all three languages. This helped us to avoid misunderstanding and any communication barrier, which could have resulted from the language used. Notes and audio-records taken during discussions were used to ensure accuracy in data collection.

3.8. PILOT STUDY

Pilot studies were carried out to test construct validity of the questionnaire. This helped to determine the content validity of the instruments and identify changes needed before they were administered. In addition, a team of health workers involved in HIV/Aids care at TRAC examined the content of the questionnaire. This helped in identifying how well respondents understood the questionnaire and how long it took, as well as in establishing its validity and whether it needed improvement. The questionnaire was therefore pre-tested with 10 adults living with HIV/Aids and five health care workers (a physiotherapist, medical doctor, nurse, nutritionist and counsellor) who did not participate in the main study.

A number of changes were made following responses given by participants. The changes that were added included the item on HIV-related health information "*Symptoms related to HIV/Aids*" and the item on services provided by health facilities, "*Services provided to family members of PLWHs*".

3.9. PROCEDURE

The procedure of data collection began with the distribution of the request letters to the State Secretary of HIV/Aids and Infectious Diseases and the Ministry of Health for their approval of the study and permission to conduct the study in the country (Appendix H & I). Permission from the authorities of the respective health facilities, in which the research was carried out, was also obtained (Appendix J).

The selection of inpatients and outpatients with HIV/Aids was based on the inclusion criteria with the help of the matrons in charge of the wards and a social worker from the HIV/Aids care unit. In addition, patients' medical files were used to get the HIV status profile and the medication that the patient was on. The matron in charge of the ward facilitated the researcher to have access to patient's file after the patient's consent in order to ensure confidentiality.

Prior to administration of the questionnaire, patients diagnosed with HIV who were admitted into the hospital who were selected by the matron in charge of the HIV wards and the researcher based on the inclusion criteria. Then after, the matron approached patients who were selected and had a one by one interaction with each HIV in order to get their consent after an explanation of the purpose of the study, their right to withdraw from the study and issues about confidentiality. Then after, HIV patients who gave their consent to the matron were later contacted by the researcher, who also obtained a verbal consent from the patients before administration of questionnaires. The above procedure was carried out by the social workers with outpatients attending HIV clinics. Each patient had a counselling session by the researcher, who is a trained counsellor, or by a counsellor from the health facilities. This was done before and after the completion of the questionnaire. The counselling session was done in order to prepare the patients about the process of the research, uplift patients' moral, especially to gain their trust and collaboration.



In addition, although patients gave their consent to participate in the study, many of them had different issues pertaining to their lives that needed to be addressed, they needed a listening ear and heart a before their share the information with the researcher.

Informed consent was obtained from health workers (Appendix M) and questionnaires were distributed to them at an agreed time. Fifty questionnaires were distributed to health workers and two hundred and fifty HIV/Aids patients were selected in conjunction with the matron of the wards for inpatients while social workers selected outpatients, based on the inclusion criteria. Two of the selected patients passed away after being selected; however, patients who died were replaced by others.

With regard to qualitative research, the *focus group discussion* was carried out with 12 PLWHs from an HIV/Aids association, namely "TWISUGANE" who were selected and agree to participate in the study by giving a consent (Appendix N).

This group of people were neither admitted to the hospital, nor were they part of the quantitative research. The main focus of the discussion was their perceived palliative care needs and their views and feelings about the palliative care and services provided to them with regard to their illnesses. The focus group discussion provided a deeper insight into met and unmet palliative care needs.

The individual interviews were conducted with four key stakeholders involved in providing HIV/Aids care or palliative care (Coordinators of HIV/Aids care Units). The main questions for the interview were their perceptions on palliative care needs of adult patients living with HIV/Aids and their views about the palliative care programme for PLWHs in terms of strengths and gaps in services for meeting both patients’ and families’ needs (Appendix F).

3.10. METHODS OF DATA ANALYSIS

3.10.1. Quantitative analysis

Questionnaires from both sets of respondents were organised into nominal, ordinal, and categorical data. After coding the data, it was entered into the Excel software program. The process of double entry was used to eliminate/minimise data entry errors. Double data entry is the process in which the data of each respondent is entered twice on separate spreadsheets in the Excel program. The Statistical Analysis System (SAS) was used to find out where errors could be by comparing spreadsheets of the entered data. After any detection of errors an immediate correction was made.

Given the descriptive nature of the study, the thrust of the data analysis was descriptive rather than inferential statistics. Both SAS and the Statistical Package for Social Science (SPSS) were used to analyse the data. Both univariate and bivariate data including frequency distributions, proportions, the mean, and cross-tabulations were used. The findings were illustrated in tables, bar and pie charts.

3.10.2. Qualitative Analysis

Analysis of the qualitative data began with the translation and transcription of interviews into English. All notes and audio taped recordings of the interviews were transcribed precisely, word for word. After reading the transcriptions of all interviews, a content analysis began and themes running through the data were identified.

The themes included were palliative care needs, financial assistance, Nutritional / food support, medical care, Anti-retroviral therapy (ART), family support, health care support, physiotherapy in palliative care, palliative care programme, home based care and quality of life. Then after, the themes were developed into categories according to the research questions/objectives. In order to maintain anonymity, participants' names were changed into codes, including the names of people living with HIV/Aids (PLWHs) and those of the coordinators. After categorising the data in line with the objectives, the results from the qualitative data were more less similar to quantitative data. However, the qualitative data gave an indepth explanation of the numerical results. In order to gain a deeper understanding of the general results, quantitative data was compared and supplemented with qualitative findings and vice versa using the process of triangulation methods (Neuman, 2000; Rees and Bath, 2001). Furthermore, in achieving the triangulation for completeness, numerical data that expanded on qualitative findings were highlighted.

3.11. ETHICAL CONSIDERATIONS

After the approval of the research proposal by the ethics committee and the Senate of the University of the Western Cape (Appendix G), further permission was requested from Ministry of Health in Rwanda and the authorities of the respective health facilities to interview both health workers and PLWHs (Appendix I). The nature, aims and importance of the study for the respondents were explained to them and their consent was sought prior to data collection. Issues of respect, confidentiality, and anonymity were explained. The right to withdraw at any time was guaranteed to every participant. Counselling was given to all patients with HIV who participated in the study. The counselling session was done in order to prepare the patients about the process of the research and to gain the trust from the patients.

3.12. SUMMARY

Chapter 3 described the methodology used in this study. It explained the research setting and the whole procedure of how the data was collected and analysed. Finally, the chapter explained how the ethical considerations applied in this study. The next chapter will discuss the results of this study.

CHAPTER FOUR

RESULTS

4.1. INTRODUCTION

In this chapter, the results are divided into **Section A**, describing results from people living with HIV/Aids (PLWHs), and **Section B**, describing results from health care providers (health care workers). The quantitative results of the socio-demographic characteristics of the study populations are described. These comprised age, gender, level of education, marital status, occupation, provinces of domicile and the knowledge of HIV health status. The main problems faced by PLWHs due to illness and their perceived palliative care needs are described. Various forms of health care support that was given, as well as their effect on PLWHs in meeting their needs, are described. Health care services including the palliative care programme available to PLWHs and their families are described. Obstacles faced by health workers in meeting optimal palliative care needs of PLWHs, and the extent to which needs are not met, are described. Findings on the level of knowledge of health workers related to HIV/Aids, palliative care for PLWHs, and the role of physiotherapy in palliative care are presented.

The qualitative results use the exact language and phrases used by the participants. However, for more clarity in the flow of ideas, the order of the contents are sometimes slightly altered. For purposes of anonymity and confidentiality, the transcribed quotations of data from the interviews are cited in the form of **PLWHs** relating to a person with HIV/Aids, and **Coordinators** relating to stakeholders/people in charge of HIV/Aids Units, to describe the voices that the interviews contained.

4.2. SECTION A PEOPLE LIVING WITH HIV/AIDS (PLWHs)

As a total of 250 participants received the questionnaires and all the participants completed the questionnaire, the response rate was 100%. Twelve PLWHs participated in a focus group discussion.

4.2.1. Socio-demographic characteristics of participants

4.2.1.1. Basic profile of participants (age, gender, marital status, level of education and occupation)

The participants' mean age was 37,7 years with a standard deviation of 9,1years. The median age was 37 years, with a minimum age of 17 years. Table 4.1 presents the socio- demographic characteristics of PLWHs who participated in the study. The majority of the participants – 176 (71%) – were females and the remaining 73 (29 %) were males. Most participants – 109 (44 %) – were widowed, and 96 (38 %) were married. The smallest number – 20 (8%) – of the participants was divorced. With regard to the participants' education, the majority – 155 (62 %) – had primary school education and only 4 (2%) had reached tertiary level. Concerning the participants' occupation, the largest proportion of participants – 153 (61,2%) – were unemployed. According to the Rwandan National Population Census (2003), a classification of unemployed people includes students, peasant farmers, housewives and other people without any occupation or job. Table 4.1 illustrates the socio-demographic characteristics of PLWHs.

Table 4.1: Socio-demographic characteristics of the study sample (n=250)

| Demographic variables | Characteristics | Frequency N | Percentage % |
|------------------------------|------------------------|------------------------|-------------------------|
| Gender | Female | 176 | 71 |
| | Male | 72 | 29 |
| Marital status | Single | 25 | 10 |
| | Married | 96 | 38 |
| | Widowed | 109 | 44 |
| | Divorced | 20 | 8 |
| Level of Education | No school attended | 42 | 17 |
| | Primary | 155 | 62 |
| | Secondary | 48 | 19 |
| | Tertiary | 4 | 2 |
| Occupation | Housewife | 15 | 6 |
| | Business | 36 | 14 |
| | Civil servant | 46 | 18 |
| | Unemployed | 153 | 61,2 |

4.2.1.2. *Participants' profiles in relation to domicile/provinces*

Most participants were from the city of the Kigali Province and Butare Province. Only two participants came from the Kibuye and Cyangugu. The findings show that most of the participants were females throughout all the provinces. Kigali Province had the highest number (121) of female participants compared to other provinces.

Concerning the occupation of the participants within their domicile, Butare province had a large proportion of participants who were unemployed compared to Kigali province, which had 59% of participants who are unemployed. The unemployed group of people included students, peasant farmers, housewives and other people without any occupation or job.

4.2.1.3. *Participants age group in relationship to their Gender*

The majority of participants –176(71%) were females and both the age group of 25-34 years; 35-44 years had had a large proportion of participants in both gender. However, the age group of 35-44 years had a large proportion –29(40%) of male participants while the age group of 25-34 years had 65(37%) of female participants. Table 4.2. Represents the breakdown of participants' Age group in relation to Gender.



Table 4.2: Represents the breakdown of participants' Age group in relation to Gender.

| Gender | Age groups | | | | |
|--------|---------------|---------------|---------------|---------------|---------------|
| | 15-24 n(%) | 25-34 n(%) | 35-44 n(%) | 45-54 n(%) | 55-64 n(%) |
| Female | 8(5) | 65(37) | 69(39) | 26(15) | 8(15) |
| Male | 3(4) | 20(28) | 29(40) | 16(22) | 4(6) |

4.2.2. HIV-related health information of participants

4.2.2.1. *The duration of knowledge of HIV-status*

Out of 250 participants, 92 (37%) participants had known their HIV-status for less than a year, 60 (24%) participants for a period of 1-2 years and only 21 (8%) participants had known their HIV-status for a period of 7-8 years. Table 4.3 illustrates the length of time that participants had known their HIV-status.

Table 4.3: The length of time participants had known their HIV- status (n=250)

| <i>HIV-status</i> | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| | <i>n</i> | <i>%</i> |
| Less than 1 year | 92 | 37 |
| 1-2 years | 60 | 24 |
| 3-4 years | 54 | 22 |
| 5-6 years | 23 | 9 |
| 7-8 years | 21 | 8 |

4.2.2.2. *The participants' length of HIV-status in relation to domicile*

Most of the participants through all 7 provinces of their domicile, had known their HIV- status for less than a year. However, in two provinces, Kigali city and Butare provinces, there were a larger proportion of participants who had known their HIV-status for 7-8 years. In Kigali city province, 13 (7,6%) participants had known their HIV-status for a period of 7-8 years while Butare province had 8 (12,3%) participants who had known their HIV-status for a period of 7-8 years. Table 4.4 illustrates the participants' length of HIV-status in relation to their domicile.

Table 4.4: The participants' length of knowledge of their HIV-status in relation to domicile (n=250)

| Province | HIV-status | | | | |
|---------------|--------------------------|----------------|----------------|----------------|-----------------|
| | Less than 1 year n | 1-2 years n | 3-4 years n | 5-6 years n | 7- 8 years n |
| Kigali -city | 63 | 41 | 39 | 15 | 13 |
| *Kigali-Ngali | 2 | | 1 | | |
| Gitarama | 1 | 2 | 1 | 1 | |
| Butare | 22 | 16 | 12 | 7 | 8 |
| Kibuye | 2 | | | | |
| Byumba | 1 | 1 | 1 | | |
| Cyangugu | 1 | | | | |



* *Kigali-Ngali: Kigali rural*

4.2.2.3. Current health status

Most of the participants had symptoms related to HIV/Aids most of the time, while 78 (31%) had no symptoms. The presence of symptoms was self-reported by patients. However, 26 (10,4%) participants had symptoms regularly. Only one participant (0,4%) was at an advanced stage of HIV. The chi-square test was done to analyse the relationship between participants' health status and limitation in ADL and thus shows that there was a significance ($p < 0.001$). Participants with no symptoms had 'better' scores than those with some symptoms. Table 4.5. illustrate the relationship between participants' health status and limitation in ADL.

Table 4.5: Illustrate the relationship between participants' health status and limitation in Activity of Daily Living (ADL), n(250)

| Health status | Limitation in Activity of Daily Living (ADL) | | | | |
|---------------|--|--------------|-------------------------|----------------------|---------------|
| | Not all n(%) | Some n(%) | Moderate amount n(%) | Quite a bite n(%) | A lot n(%) |
| No symptoms | 75(53,5) | 36(25,7) | 22(15,7) | 5(3,7) | 2 (1,4) |
| With symptoms | 23(21) | 28(25,4) | 41(37,2) | 14(12,7) | 4(3,6) |

4.2.2.4. *Symptoms related to HIV/Aids*

PLWHs indicated various symptoms related to HIV/Aids. The most prevalent symptom reported was pain – 118(47, 2%), 89 (36%) participants experienced numbness in both hands and feet, 63 (25%) participants had tingling in both hands and feet and 44 (17,6%) participants had general weakness. Table 4.6 illustrates the prevalence of PLWHs experiencing symptoms related to HIV/Aids.



Table 4.6: Frequency of symptoms in people living with HIV/Aids (n=250)

| Symptoms | Frequency | Percentage |
|--------------------------------|------------------|-------------------|
| | n | % |
| Chest-pain | 1 | 0,4 |
| Shoulder pain | 1 | 0,4 |
| Hypertension | 1 | 0,4 |
| Amnesia | 2 | 0,8 |
| Depression | 2 | 0,8 |
| Paraparesis | 3 | 1,2 |
| Skin rash | 3 | 1,2 |
| Oedema of the feet | 4 | 1,6 |
| Fever | 5 | 2 |
| Joint stiffness | 5 | 2 |
| Hemiparesis | 6 | 2,4 |
| Nausea | 9 | 3,6 |
| Weight loss | 9 | 3,6 |
| Dizziness | 9 | 3,6 |
| Backache | 17 | 6,8 |
| Lack of appetite | 20 | 8 |
| Diarrhoea | 21 | 8,4 |
| Cough | 26 | 10,4 |
| Vomiting | 27 | 10,8 |
| Muscle soreness | 32 | 12,8 |
| Herpes zoster | 33 | 13,2 |
| General weakness | 44 | 17,6 |
| Tingling in both hand and feet | 63 | 25,2 |
| Numbness of both hand and feet | 89 | 35,6 |
| Pain | 118 | 47,2 |



The numbness and paraesthesia in hands and feet were most common symptoms among PLWHs. This is mainly due to the side effect of certain drugs, as one participant explained during the interviews:

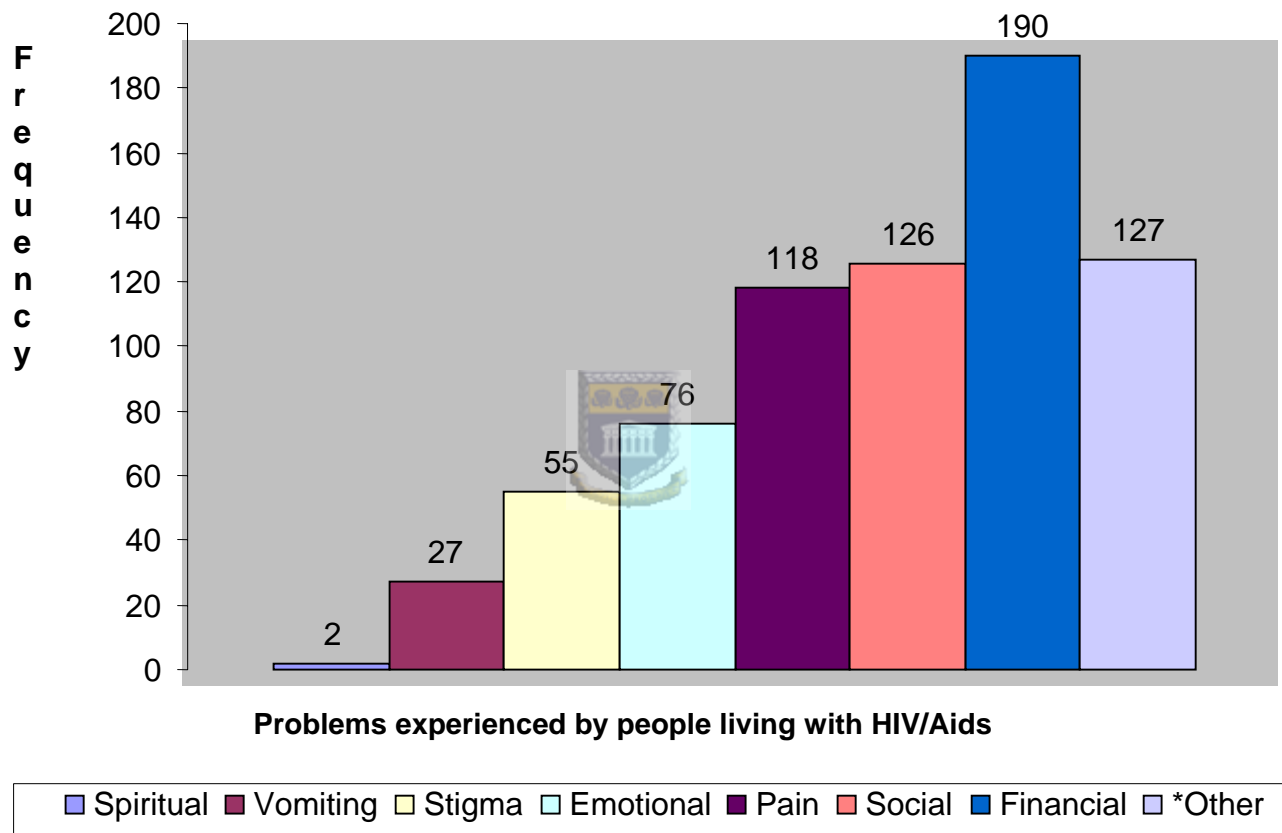
Most of the patients have many neurological cases such as facial palsy, hemiparesis, Paraparesis and herpes zoster due to the side effect of most of the ARVs drugs such D4T and NIH for those who have a TB. (Coordinator)

In addition, the chi-square test was done to test the relationship between presence of symptoms and occupation (unemployment) of participants. The results show that there was no significance ($p = 0.44$).

4.2.3. Problems experienced by participants as a result of illness

With regard to identifying problems faced mainly by PLWHs due to their illness, participants had an option to tick more than one answer. Financial problems, social problems and pain were the major problems that PLWHs experienced as a result of their illness. However, the majority of participants reported facing financial problem as a result of illness. Figure 4.4 gives an illustration of problems faced by PLWHs due to their illness.

Figure 4.1: Problems experienced by people living with HIV/Aids as results of illness



**Other problems included unemployment, lack of food and weight loss.*

Pain and vomiting were identified as symptoms related to HIV/Aids (Table 4.6). Participants identified pain and vomiting as problems in figure 4.2.

From the interviews, there was a further explanation from both PLWHs and coordinators on why PLWHs had financial problems as result of the illness:

I have 4 kids but it is difficult for me to take them at the hospital for an HIV test because it requires money and I do not have. (PLWHs)

In addition, one of the participants further explained that poverty was the root of financial problems that PLWHs experienced:

As you know, there is a quite a big number of Rwandese population who lives below the poverty line. If someone gets infected their income goes down and he/she can't produce any longer to support him/herself and the family. (Coordinator).

The coordinators gave further explanations about poverty leading to financial problems and how it was hindering health care providers/stakeholders in providing full palliative care to PLWHs. One of the participants explained:

Drugs for treatment of opportunistic infections are very expensive and patients cannot afford the price. Hospitals do provide drugs for treatment of opportunistic infections but they are not sufficient. We need more drugs so that all patients can have access to them. Moreover, palliative care requires lots of investments and equipment, yet poverty has struck the country. (Coordinator)

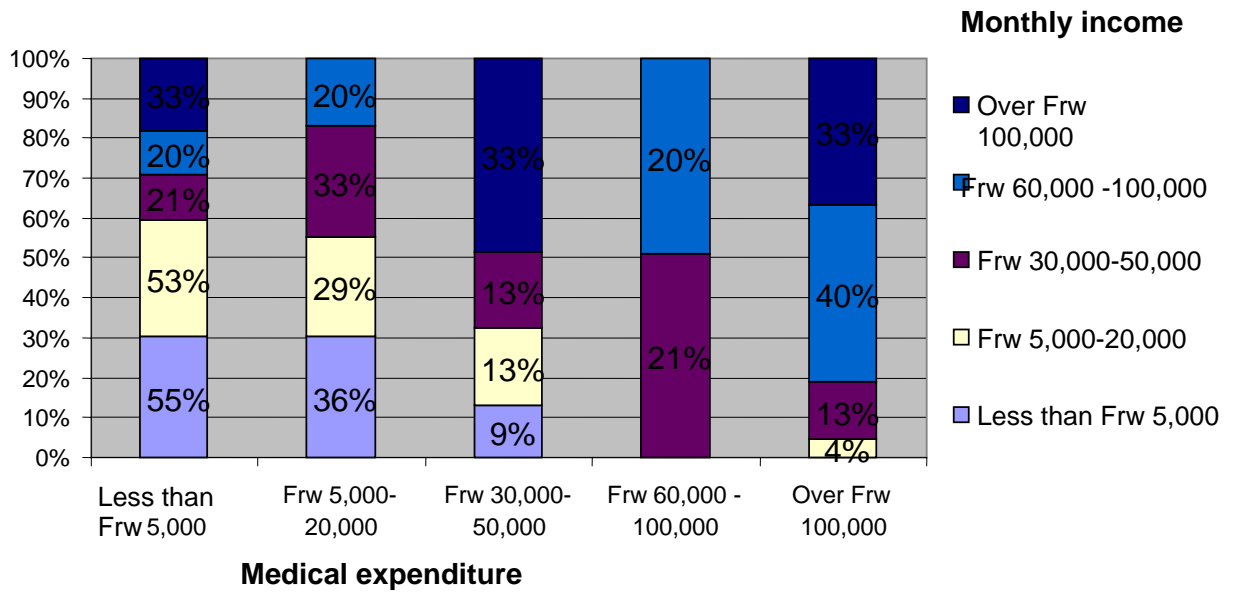
4.2.3.1. Monthly income of people living with HIV/Aids

The majority of participants earned a monthly income of Frw 5,000 –20,000), 24 (27%) participants earned between (Frw 30,000-50,000) and 11(13%) participants earned less than Frw 5,000. A smaller proportion – 5 (7%) – participants had a monthly income which ranged between (Frw 60,000-100,000) and 3 (3%) participants earned over Frw – 100,000 per month.

4.2.3.2. Medical expenditure and monthly income of people living with HIV/Aids

Among 45 participants who had a monthly income of (Frw 5,000-20,000), most of the participants – 24 (53%) – spent less than 5,000 Frw on medication monthly and two (4%) participants spent over 100,000 Frw – on brand new drugs on a monthly basis. Of the 24 participants who had a monthly income of Frw 30,000-50,000, a large proportion – 8 (33%) participants spent Frw 5,000-20,000 per month on medication and only 5 (21%) participants spent less than 5,000 Frw per month on medication. Among the participants – 5 (6%) who had a monthly income of Frw 60,000-100,000, 2 (40%) participants spent over Frw 100,000 per month on medication. The trend in differences on medical expenditure might be due to the fact participants who spent less on medication gets ARVs free of charge as well as treatment of OIs. For participants who could spend more than what they earn might also be due to the various reasons such as having support from HIV/Aids international organisations or a family member. Figure 4.2 illustrates the monthly medical expenditure of PLWHs

Figure 4.2: Relationship between medical expenditure and monthly income



4.2.4. Perceived palliative care needs

In identifying palliative care needs of PLWHs, participants had to tick all that applied to their needs. There were 14 needs identified by PLWHs. A large proportion of participants identified the need for financial assistance. From interviews, participants explain the need for financial assistance:

I need a financial assistance so that my kids will continue to go to school (PLWHs).

The second greatest need was home-based care (HBC) as reported by 155 (62%) participants. Participants gave an in-depth explanation on the need for HBC:

We also need home-based care where you can receive the care at home. Sometimes it is difficult to get at the hospital for treatment due to sickness or transport. I would prefer to be looked at home (PLWHs).

Another participant further explained:

Regular visits at home help a lot because you feel not stigmatized or discriminated. It also helps health workers to know in which ways or condition that I am in so that they will know what I need as support. (PLWHs)

The need for nutrition/food was also reported as the third greatest need reported by 111 (44%) participants. One participant explained:

ARVs help a lot but it requires having enough food because if you do not have food the drugs will weaken you much more and cause you problems. There are some of our friends in the group who did not have a good adherence because of lack of food. (PLWHs)

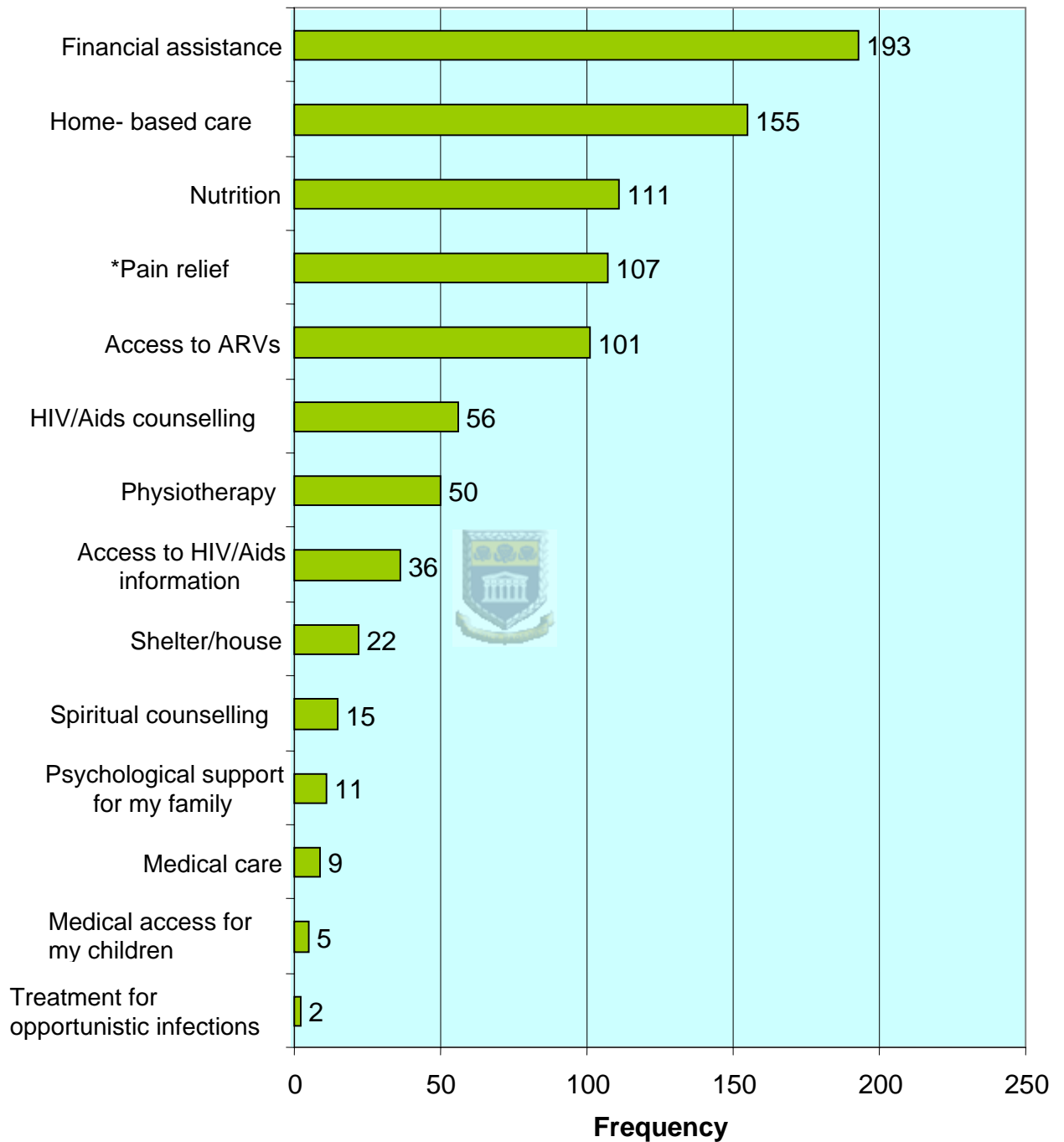
Furthermore, one of the stakeholders providing HIV/Aids care at the National Treatment and Research AIDS Centre (TRAC) stressed nutritional support to PLWHs as part of palliative care:

It is only not a need for medical care but the nutritional support is also needed as palliative care is concerned. The government should provide that. (Coordinator)

The fourth greatest palliative care need expressed by PLWHs was pain relief, which was reported by 107 (43%) participants and access to ARVs was also reported by 101 (40%) participants. In addition, 50 (20%) participants identified the need for physiotherapy . Figure 4.3 illustrates perceived palliative care needs of PLWHs.



Figure 4.3: Perceived palliative care needs of people living with HIV/Aids (n=250)



* Pain relief includes symptom management

Other palliative care needs, possibly not as great priority as the first four were: access to medical care for their families, counselling services and housing.

One participant gave a more detailed explanation about access to medical care for their families:

Some of us have children and husbands who are sick too, but the medical care provided to us does not cater for our children. (PLWHs)

Another participant added information by stating that:

We need also counselling service, which will provide psychological support towards my family. (PLWHs)

In addition, one of the participants clarified the need for housing:

Some of us we do not have nice houses. My house is a house which is in bad condition because it sink, when the rain comes it enters my house thus make me to fall sick regularly due to the poor condition of my house (PLWHs).

4.2.5. Support given to participants in relation to their needs

This section looks at the support PLWHs received for pain relief, physiotherapy, and psychological and financial problems. It also looks at support given to PLWHs who are admitted in the hospital and those who are at home, and which ways they were meeting their needs.



4.2.5.1. Support provided to people living with HIV/Aids for pain

Various forms of support or treatment were given to meet participants' needs. One hundred and eighteen participants had pain and 90 (76,2%) - participants received treatment to alleviate their pain. Of the 90 participants who received treatment for pain, 35 (42%) reported that the treatment helped a little bit, 23 (27%) participants reported it helped quite a lot and 19 (23%) participants reported that it did not help. A few participants – 7 (8%) – said that the treatment helped a lot in meeting their needs.

4.2.5.2. Support provided to people living with HIV/Aids for psychological/ emotional problems

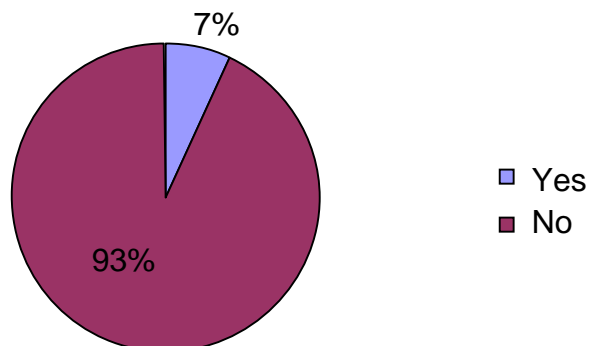
The majority of participants -151 (65%)- had psychological problems and most of them had received psychological treatment or support.

Out of the 94 participants who received psychological support, 10 (11%) participants said that the treatment or support helped a lot, while 3 (3%) of participants reported that the treatment did not help.

4.2.5.3. *Support provided to people living with HIV/Aids for physical problems*

With regard to physical problems, only 11 (7%) of the participants had physiotherapy. Figure 4.4 illustrates what percentage of people received physiotherapy treatment.

Figure 4.4: Physiotherapy treatment



Among the 11 participants who received physiotherapy, the majority of participants – 10 (90%) – had massage as their treatment and only one participant had mobilization of joints as treatment. Out of the 10 participants who had massage, the majority 8 (80%) of participants reported that massage helped them and 6 (75%) participants reported that electrotherapy helped. Table 4.7 summarizes the physiotherapy treatment that was given and its effectiveness.

Table 4.7: Physiotherapy treatment and its effectiveness (n=11)

| <i>Type of physiotherapy</i> | <i>Physiotherapy treatment given</i> | | <i>Treatment helped</i> | |
|------------------------------|--------------------------------------|----------|-------------------------|----------|
| | | <i>n</i> | | <i>n</i> |
| Massage | | 10 | | 8 |
| Electrotherapy | | 8 | | 6 |
| Exercise-therapy | | 4 | | 2 |
| Mobilization | | 1 | | 1 |

The low percentage of participants who had access to physiotherapy treatment is supported by one of the participants' views:

Physiotherapy is really a need. But the major problem is access to it. It is a separate service. We have to pay for it and we cannot afford that. (PLWHs)

Furthermore, one coordinator of a HIV/Aids unit highlighted the fact that physiotherapy treatment was not reaching PLWHs who was in need:

Patients do not receive physiotherapy treatment as part of palliative care. We do not have many physiotherapists in the country that could provide physiotherapy treatment, although it is really needed by AIDS patients. (Coordinators)

4.2.5.4. Support provided to people living with HIV/Aids for financial problems

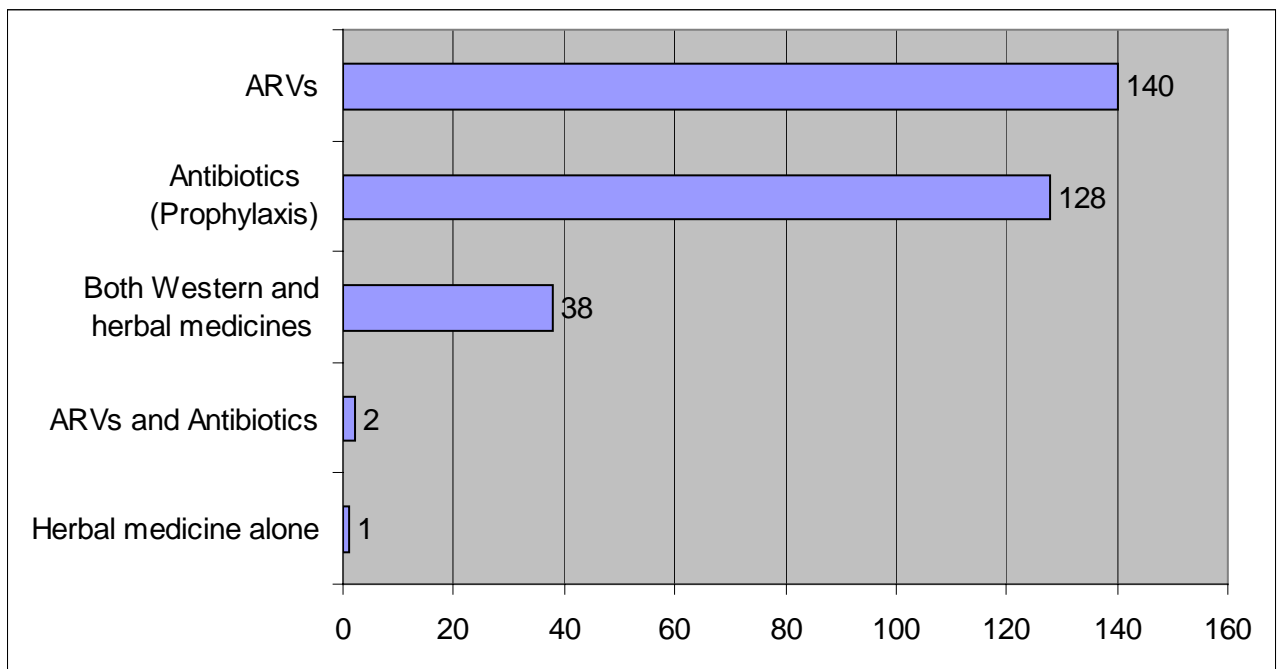
The majority of participants – 207 (91%) – reported having financial problems and only three (1%) of these participants received financial support. Out of the three participants who received financial support, only one (33%) participant had a support, which helped a lot.

4.2.5.5. Medication

In identifying different medication used by PLWHs, the results show that some patients used more than one kind of medication. Figure 4.5 illustrates that of the 250 participants, 140 (56%) were on anti-retroviral drug, 128 (51%) were on antibiotics (prophylaxis) and 38 (15%) were on both Western medicines and herbal medicine. Only one (0, 4%) participant used herbal medicine alone.



Figure 4.5: Proportion of participants using different forms of medication (n=250)



Participants expressed their views and feelings about the medical support in terms of ARVs received from health care providers in meeting their palliative care needs:

Since I started the ARVs, my CD⁴ cells count has increased. (PLWHs)

Another participant said:

When you are admitted in the hospital, there is no proper follow-up by health care workers. You are the only one who takes care of yourself. Apart from medical support there is no another support available for you. (PLWHs)

Another participant commented on the support provided:

The medical care that we received is not proportional because only those who have a CD⁴ count which is low, that means 200/mm³, are the ones who have access to medical care such as ARVs and receive other support like food. But for us who have a CD⁴ count above 200/mm³ we do not have access to medical care, yet we are still sick. (PLWHs)

Furthermore, the in-depth interviews with coordinators of HIV/Aids units give clarification and meaning with regard to palliative care services provided to PLWHs and the extent to which Aids patients' needs are met, as the interview extract reveals:



The services provided by the palliative care team are very poor. We only concentrate on ARVs while we could incorporate other service such as home based care, nutrition and other support required by the patients. So far we have just covered 50% of the efficacy of AIDS care. Palliative care is still a new concept; that is why not much has yet been done. (Coordinator)

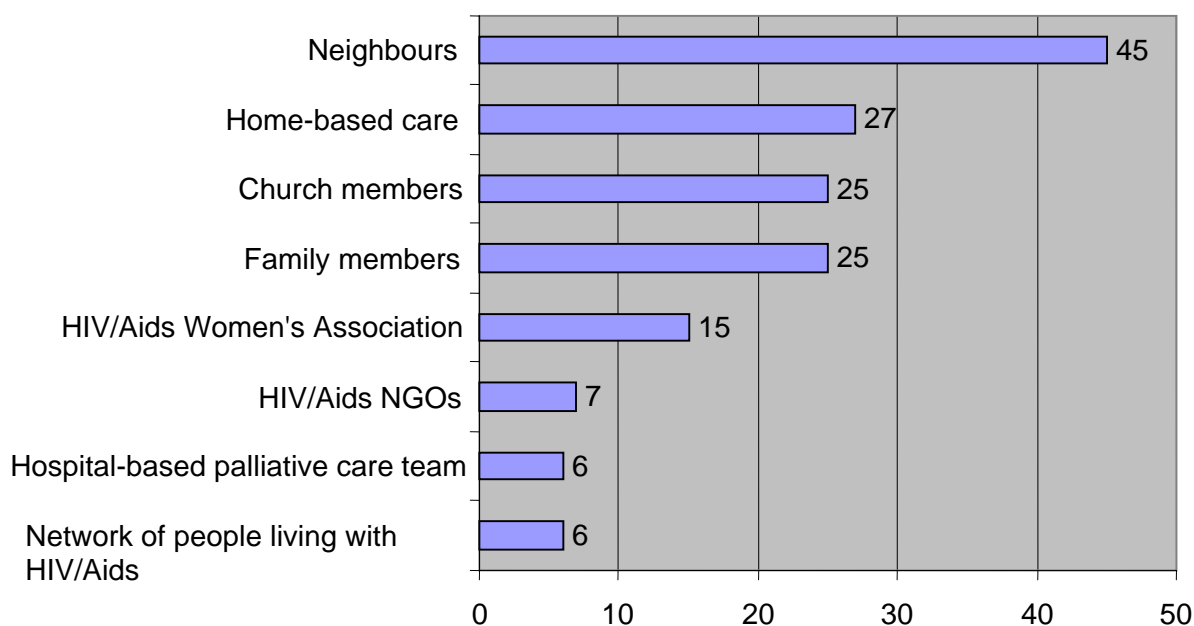
4.2.6. Hospitalisation and visits

Most of the participants – 139 (56%) – had been admitted to the hospital at some time or other, while 110 (44%) participants had never been admitted. The majority of participants – 154 (61,6%) – who were either admitted to hospital or cared for at home did not receive regular visits from the palliative care team .

4.2.6.1. Source of people who visited patients living with HIV/Aids

People who visited PLWHs while they were hospitalized and cared for at home came from various places and organizations. The largest proportion of participants – 45 (56%) – were visited by people from the neighbourhood and 27 (18%) participants were visited by the HBC team while they were at home. Only six (13%) participants who had been admitted to hospital were visited by the hospital-based palliative care team. Figure 4.6 illustrates this.

Figure 4.6: Type of people regularly visiting patients living with HIV/Aids in hospital and at home (250)



4.2.7. Hospital palliative care and home-based care

These findings focus on the support provided by both hospital-based palliative care and home-based care teams.



4.2.7.1. Support provided to people living with HIV/Aids by Hospital-based palliative care (HPCT) and Home-based care team (HBCT)

All six participants who have been visited by HPCT received medicines (ARV), and financial support . While out of 27 participants who have been visited by HBCT, only 9 (33%) received medicines (ARVs). Of the six participants visited by HPCT, all received financial support, while only 2 (7%) participants of 27 visited by HBCT did receive financial support. Table 4.8 illustrates the support provided to both, and HBCT administered to PLWHs.

Table 4.8: Support given to people living with HIV/Aids by hospital palliative care and home-based care teams

| Support given | Hospital-based palliative care team | Home-based care team |
|----------------------|--|-----------------------------|
| | n=6 n (%) | n=27 n (%) |
| Medicines | 6 (100) | 9 (33) |
| Counselling | 6 (100) | 27 (100) |
| Food/Nutrition | 1(16) | 10 (37) |
| Financially | | 2 (7) |
| Legal issue | | 1 (4) |

One of the participants further explained why the HPCT does not provide enough support to HIV/ Aids patients:

For those who are admitted to hospital, nothing much has been done because of various reasons such as lack of skilled health workers. HIV/Aids patients need a lot of time, more than any other patients, especially when he/she has reached the stage of getting palliative care. Again, most of nurses do not have any knowledge on palliative care. (Coordinator)



4.2.8. Preferred setting for care in phase of terminal illness

Most of the participants – 168 (67,2%) – indicated that they would prefer to be looked after in hospital during the terminally ill phase. However, 65 (26%) participants indicated that they preferred to be looked after at home, while only 6 (2, 4%) participants preferred to be looked after at a home-based care centre. Table 4.9 illustrates this.

Table 4.9: Preferred setting for care in phase of terminal illness (n=250)

| <i>Place to be looked after</i> | <i>Frequency N</i> | <i>Percentage %</i> |
|---------------------------------|------------------------|-------------------------|
| Hospital | 168 | 67,2 |
| Home | 65 | 26 |
| Do not mind | 10 | 4 |
| Home-based care centre | 6 | 2,4 |
| Church | 1 | 0,4 |

4.3. Section B HEALTH WORKERS INVOLVED IN HIV/AIDS CARE

A total of fifty questionnaires were distributed to health workers including medical doctors, nurses, counsellors, physiotherapists, nutritionists and social workers involved in HIV/Aids care provided by health facilities included in the study. Forty questionnaires were returned, giving a response rate of 80%. In addition, four coordinators of HIV/Aids units were interviewed individually.



4.3.1. Socio-demographic Characteristics

The mean age of the participants was 36.9 years, (SD= 8.3 years) while the minimum age was 24 years and the maximum 52 years. The majority of the participants were females 24 (60%). The large proportion of 13 (32,5%) participants had an advanced diploma. Eleven (27,5%) participants were nurses, 10 (25%) participants were medical doctors and 3 (7,5%) participants were physiotherapists. Twenty-one (53%) of the participants were working in a general hospital (inpatient) section, while a smaller proportion of participants – 7 (18%) – were working in a hospital-based palliative care section, and 3 (8%) of the participants were working in a home-based care section. Table 4.10 illustrates the socio-demographic characteristics of health workers in detail.

Table 4.10: Socio-demographic characteristics of health workers (n=40)

| <i>Variables measured</i> | <i>Characteristics</i> | <i>Frequency</i> | <i>Percentage</i> |
|---------------------------|--------------------------------|------------------|-------------------|
| | | <i>n</i> | <i>%</i> |
| Gender | Female | 24 | 60 |
| | Male | 16 | 40 |
| Level of education | Bachelor's degree (Ao)* | 12 | 30 |
| | Advanced diploma (A1)** | 13 | 32,5 |
| | Secondary diploma (A2)*** | 12 | 30 |
| | Primary level certificate (A3) | 2 | 5 |
| | Vocational training | 1 | 2,5 |
| Qualification | Nurse | 11 | 27,5 |
| | Medical doctor | 10 | 25 |
| | Counsellor | 7 | 17,5 |
| | Dietician/ Nutritionist | 4 | 10 |
| | Social health worker | 4 | 10 |
| | Physiotherapist | 3 | 7,5 |
| | Other | 1 | 2,5 |
| Main working section | Hospitalisation (Inpatient) | 21 | 53 |
| | Consultation | 18 | 45 |
| | Hospital-based palliative care | 7 | 18 |
| | Home-based care | 3 | 8 |
| | Other | 4 | 10 |

*Ao= is equivalent to a honours degree in SA (4 years undergraduate)

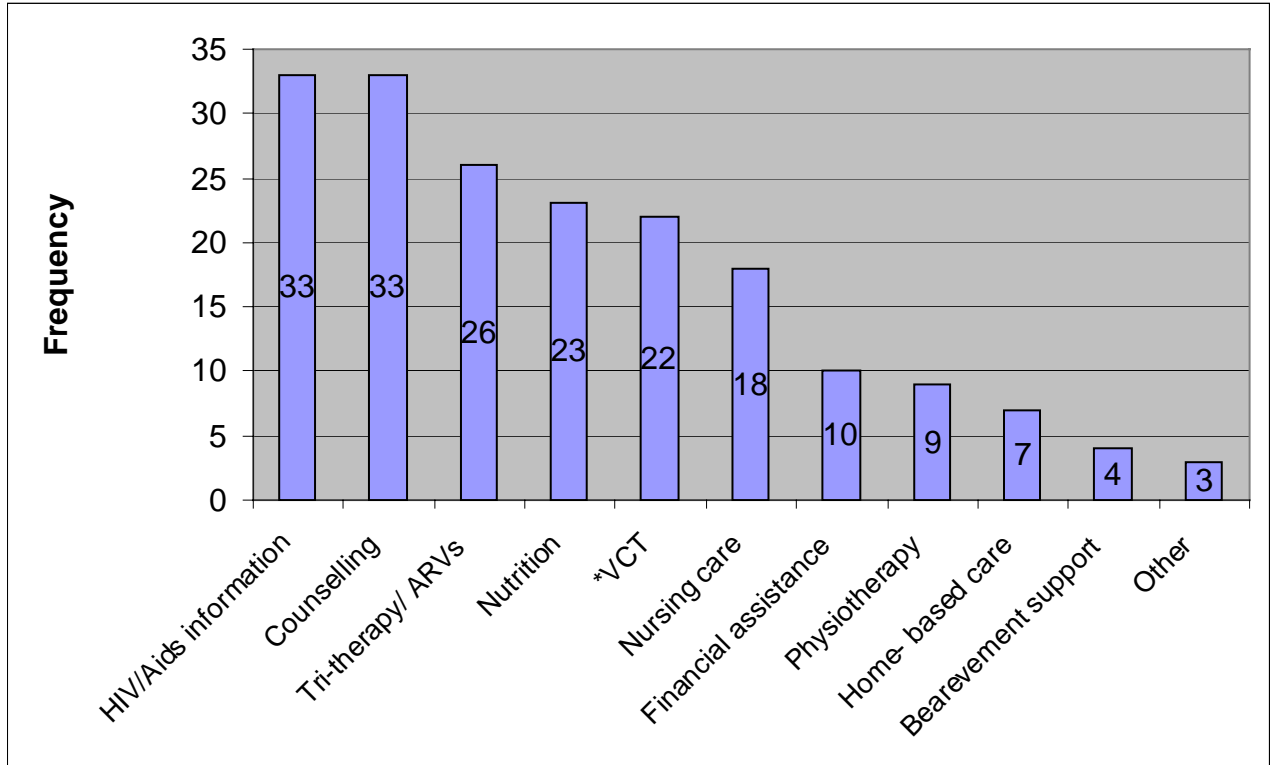
**A1= is equivalent to a bachelor's degree in SA (3 years undergraduate)

***A2= is equivalent to matric level

4.3.2. Health care services provided to PLWHs and their families

The majority of the participants said counselling and HIV/Aids information were provided to PLWHs, 26 (65%) participants said that they provided Tri-therapy/ARVs to PLWHs at their health facilities. Only 4 (10%) participants said that they provided bereavement support to PLWHs. The figure 4.8 illustrates the health care services provided to people living with HIV/Aids (PLWHs).

Figure 4.8: Health care services provided to people living with HIV/Aids (n=40)



*VCT: Voluntary counselling and testing



*Bereavement support includes counselling of the families members when they have lost their loved one, as well as funeral assistance and legal support.

Participants reported on services that they provide to the families of PLWHs at their health facilities. The majority of participants indicated that their health facility provides financial support, while few participants – 7 (18%) – indicated their health facility provided bereavement support to families of PLWHs. Table 4.11 illustrates these health care services provided to families of PLWHs.

Table 4.11: Services provided to families of people living with HIV/Aids (n=40)

| Variable | Characteristics | Frequency n | Percentage % |
|--|------------------------|------------------------|-------------------------|
| Services provided to families of PLWHs | Financial support | 31 | 78 |
| | Counselling | 30 | 75 |
| | HIV/Information | 17 | 43 |
| | Bereavement support | 7 | 18 |

In spite of these services provided to family members of PLWHs, the care of family members was difficult:

It is quite difficult to provide any support to family members of PLWHs, especially to husbands, because most of the patients are married illegally. This hinders the proper medical care of patients, since most of the husbands do not turn up at the hospital for counselling and testing. (Coordinators)



4.3.3. Palliative care Services to people living with HIV/Aids

4.3.3.1. Palliative care programme

The palliative care programme consists of a package of different forms of care or services, including palliative care education, bereavement, inpatient hospital care (general hospital care) HBC, inpatient palliative care (hospital-based palliative care), financial assistance, nutrition support, HBC and other supports that help to alleviate pain and improve the quality of life of PLWHs and their families.

The majority of the participants reported that they provide general hospital care, 11 (27,5%) participants provided palliative care education and 10 (25%) participants provided financial assistance services as part of their palliative care programme. Five (12.5%) participants provided bereavement support. Table 4.12 illustrates the palliative care programme for PLWHs provided by health care facilities.

Table 4.12: Palliative care programmes (n=40)

| <i>Variable</i> | <i>Characteristics</i> | <i>Frequency n</i> | <i>Percentage %</i> |
|---------------------------|---------------------------|------------------------|-------------------------|
| | Inpatient palliative care | 24 | 60 |
| Palliative care Programme | Palliative care education | 11 | 27,5 |
| | Financial assistance | 10 | 25 |
| | Bereavement support | 5 | 12,5 |
| | Home-based care | 5 | 12,5 |

4.3.3.2. Palliative care team

The majority of participants – 24 (62%) – reported that they had a palliative care team at their workplace. Table 4.14. illustrates the reported existence of palliative care teams at different health facilities.

Table 4.13: Provision of a palliative care team at different health facilities

| <i>Palliative care team</i> | <i>Settings (Health Facilities)</i> | | | | | |
|-----------------------------|-------------------------------------|-----------------------|----------------------|------------------------------|----------------------|----------------------|
| | CHUK n (%) | CHUB n (%) | DHK n (%) | CLINIC TRAC n (%) | CPB n (%) | CSK n (%) |
| YES | 6 (67) | 5 (62,5) | 3 (60) | 2 (40) | 6 (100) | 3 (43) |
| NO | 3 (33) | 3 (37,5) | 2 (40) | 3 (60) | | 4 (57) |
| TOTAL | 9 | 8 | 5 | 5 | 6 | 7 |

Note: The percentage is calculated based on the number in each column.

In six of the health facilities, health workers were not consistent in their response with regard to the existence of palliative care at their hospitals. Only at Centre Psycho-social de Biryogo (CPB), were all health workers consistent in their response.

In the statement below one participant further explained the lack of a palliative care team in many health facilities:

There is no unit, which is specifically for palliative care. Those who provide palliative care do not form a team as such, but the care is delivered at the departmental level. (Coordinator)

For those who had a palliative care team, the service did not appear to be well provided due to a lack of a common understanding of palliative care. From the interviews, one of the participants further explained:

The service or the team is there, but it does not provide a proper palliative care to AIDS patients and their families. We still need a lot to provide good care. Since, all of us as a team do not comprehend palliative care in the same way. (Coordinators)

Seventeen (43%) participants reported that social workers were usually members of a palliative care team, participants 16 (40%) reported medical doctors and 15 (38%) participants reported nurses as members of palliative care team. A smaller number of participants – 5 (13%) mentioned that physiotherapists and dieticians were also members of the palliative care team at their health facilities. Table 4.14 illustrates members of palliative care team.

Table 4.14: Members of a palliative care team

| Variable | Characteristics | Frequency n | Percentage % |
|--|--|------------------------|-------------------------|
| Members of Palliative care team (MPCT) | Social worker | 17 | 43 |
| | Medical doctor | 16 | 40 |
| | Nurse | 15 | 38 |
| | Volunteer | 9 | 23 |
| | Health educators | 6 | 15 |
| | Religious leaders | 6 | 15 |
| | Dietician | 5 | 13 |
| | Physiotherapist | 5 | 13 |
| | Others (pharmacist, counsellors, community health workers) | 7 | 18 |

4.3.4. Palliative care needs and obstacles to meeting the needs of PLWHs and their families

4.3.4.1. *Human Resources for meeting palliative care demands/needs of people living with HIV/Aids and their families*

Out of 40 participants, 29 (78%) – indicated that they did not have enough staff to meet palliative care needs of PLWHs and their families. Among the 29 participants who did not have enough staff to meet palliative care needs of patients and their families, the large proportion of participants – 14 (48%) – indicated that they needed an increase of 25% in staff, while 2 (7%) participants needed an increase of 100% in staff. Table 4.15 illustrates the increase in staff required to meet palliative care needs of PLWHs and their families.

Table 4.15: The increase in staff required to meet palliative care needs of people living with HIV/Aids and their families (n = 29)

| Increase in staff | Frequency n | Percentage % |
|-------------------|----------------|-----------------|
| 25% of staff | 14 | 48 |
| 50% of staff | 12 | 41 |
| 75% of staff | 1 | 3 |
| 100% of staff | 2 | 7 |

Note: The above results give a reflection from health workers from different health facilities.

The clarification on the need for an increase in staff was echoed in the following statements, as one participant has said:

The need for an increase in health workers who are skilled, is to enable them to deliver palliative care service to people who require it. (Coordinators)

Concerning the equipment, the majority of participants – 35 (87,5%) – reported that they did not have enough equipment at their workplace, and only 4 (10%) participants said that they had enough equipment. The majority of participants – 18 (51,4%) – wanted 50% more equipment. Four (11,4%) participants said that they needed 100% more equipment at their workplace to meet palliative care needs of PLWHs and their families. Table 4.16 illustrates the increase in equipment required to meet palliative care needs.

Table 4.16: Equipment required to meet palliative care needs of people living with HIV/Aids and their families (n=35)

| Increase in equipment | Frequency n | Percentage % |
|------------------------------|------------------------|-------------------------|
| 25% in equipment | 11 | 31,4 |
| 50% in equipment | 18 | 51,4 |
| 75% in equipment | 2 | 6 |
| 100% in equipment | 4 | 11,4 |

Note: The above results give a reflection from health workers from different health facilities.

The kind of equipment needed was described as follows:

We need equipments such as motorbikes to facilitate transport for health workers who go for home-based care. We also need a department which is well-equipped with a computer so that we can have a database of information on patients' needs and the services provided, as well as hospital wards which will be specifically for patients under palliative care. (Coordinators)

In addition to an increase of staff and equipment, other need were expressed:

If we are to meet the needs of patients and their families, we need to strengthen the Unit of HIV/Aids care and physiotherapy, set up a rehabilitation and nutrition service for PLWHs. All hospitals should have sufficient drugs other than ARVs that can alleviate the pain of the patients, including drugs for treatment of opportunistic infections so that all patients can have access. (Coordinators)

4.3.4.2. *Obstacles to meeting palliative care needs of PLWHs and their families*

The participants indicated the obstacles they are faced with in trying to meet the palliative care needs of PLWHs and their families. Table 4.17 illustrates the obstacles that make it difficult to meet palliative care needs of PLWHs and their families.

Table 4.17: Obstacles in meeting palliative care needs of people living with HIV/Aids and their families (n=40)

| <i>Variable</i> | <i>Characteristics</i> | <i>Frequency n</i> | <i>Percentage %</i> |
|--|--|------------------------|-------------------------|
| Obstacles in meeting palliative care needs of PLWHs and their families | Lack of appropriate space for counselling sessions | 27 | 68 |
| | Lack of funding | 24 | 60 |
| | Rwandese culture | 15 | 38 |
| | Lack of policy on palliative care | 11 | 28 |
| | Lack of skills | 10 | 25 |
| | Stigma around HIV/Aids | 9 | 23 |
| | Lack of time | 2 | 5 |

4.3.5. Training and knowledge of palliative care

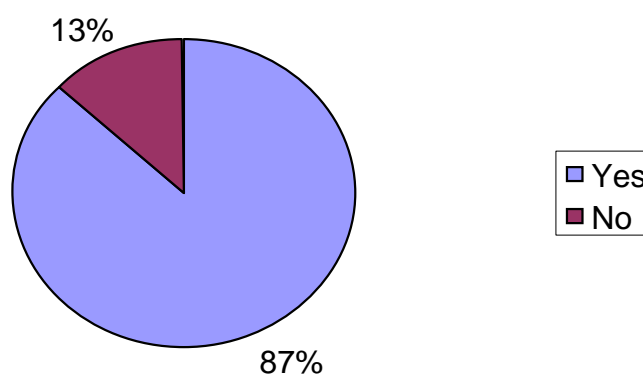
This section indicates the training and reported knowledge of health workers in relation to HIV/Aids issues and palliative care.



4.3.5.1. Training in HIV/Aids related issues

The majority of the participants – 35 (87%) – had received training on HIV/Aids-related issues. Figure 4.9 illustrates the training of participants in HIV/Aids-related issues.

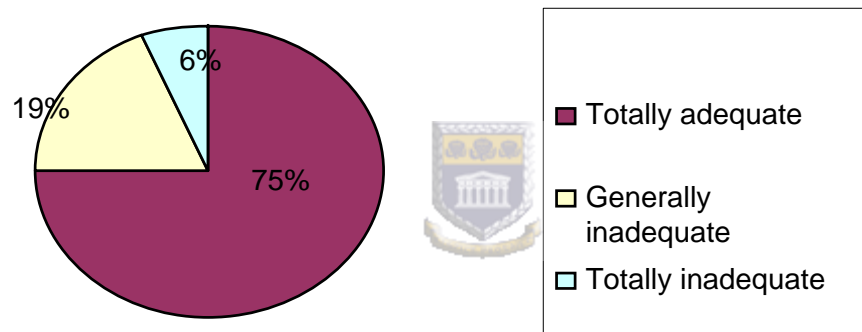
Figure 4.9: Training of participants in HIV/Aids-related issues



4.3.5.2. *Training and knowledge on palliative care knowledge for adults living with HIV/Aids*

The majority of participants – 24 (60%) – reported that they had not received any training while only 16 (40%) of participants had received training related to palliative care in relation to adults living with HIV/Aids. Of the 16 participants who had training in palliative care, the majority of participants – 12 (75%) – reported that they felt they had adequate knowledge of palliative care and only three (19%) participants felt that they had inadequate knowledge on palliative care. Figure 4.10 illustrates the adequacy of health care providers’ training on palliative care for adults living with HIV/Aids.

Figure 4.10: Adequacy of health care providers’ training on palliative care for adults living with HIV/Aids (n=16)



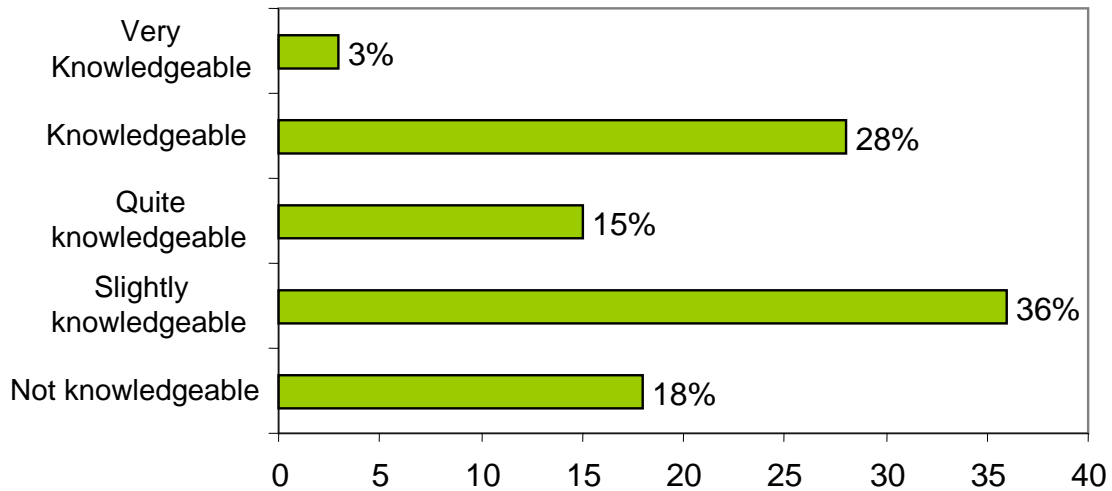
4.3.6. **Physiotherapy and palliative care for people living with HIV/aids**

This section will describe the reported knowledge of health workers on the role of physiotherapy in palliative care for PLWHs.

4.3.6.1. *Role of physiotherapy in palliative care*

Most of the participants – 14 (36%) – indicated that they were “slightly knowledgeable” about the role of physiotherapy in palliative care; 7 (18%) indicated that they were “not knowledgeable” about the role of physiotherapy in palliative care and only 11 (28%) participants indicated that they were “knowledgeable” about the role of physiotherapy in palliative care. The figure 4.11 illustrates this.

Figure 4.11: Self-rating: the knowledge of health workers about the role of physiotherapy in palliative care (n=39)



One of the participants further explained why physiotherapy had a role in palliative care for PLWHs:

We do see the role of physiotherapy in palliative care, especially in cases where most of the patients have many neurological problems such as facial palsy, hemiparesis, paraparesis, and herpes zoster due to the side effect of most of the ARV drugs such as D4T, and NIH for those who have a TB. (Coordinator)

Furthermore, another participant explained:

Yes, I do see the role of physiotherapy in palliative care for PLWHs, but it is still a theory. Patients do not receive physiotherapy treatment as part of palliative care. We do not have many physiotherapists in the country that could provide physiotherapy treatment. (Coordinators)

4.4. SUMMARY

This chapter presented the findings of the study. The results showed that the age group of 15-24 years of female participants had three times the number of male participants in the same age group. In addition, there was significance between the participants' health status and participation in ADL ($p < 0.001$) patients with no symptoms had a better score in participation of ADL.

Palliative care needs of PLWHs were perceived in a similar way by PLWHs and health care providers, the latter included health care workers and HIV/Aids coordinators. The needs that were identified by PLWHs comprised the need for: treatment for opportunistic infections, medical access for their children, medical care, psychological support for families, spiritual counselling, shelter, access to HIV/Aids information, physiotherapy, HIV/Aids counselling, access to ARVs, pain relief and management of other symptoms, nutrition, HBC and financial assistance. The level of unemployment of PLWHs was high (61,2%) and the majority of PLWHs in Butare Province were unemployed compared to Kigali province.

The most common palliative care needs perceived by PLWHs were the need for financial assistance, HBC, nutritional/food support, pain relief and management of other symptoms, access to medical care which includes access to ARVs, treatment of opportunistic infections, and medical care of the family.

According to the health care workers, various health care services such as voluntary counselling and testing (VCT), HIV/Aids information, Anti-retroviral therapy, psychological/emotional support, HBC, bereavement support, inpatient palliative care, education on palliative care, financial support and food were provided to PLWHs and their families to meet their palliative care needs. However, health care providers reported that voluntary counselling and testing (VCT), HIV/Aids information, Anti-retroviral therapy, financial support and food were the services most frequently provided.

Some contradictions emerged with regard to financial services. The majority of health workers (78%) reported that their health facilities provided financial assistance to family members of PLWHs, while only 1% of PLWHs reported having received a financial support.

Despite the availability of health care services for PLWHs and their families, and the provision of other support, most of the palliative care needs were still unmet, especially pain relief and symptom management, and financial and nutritional needs. In addition, over 50% of health care workers reported that they did not have human resources and equipment to meet the demands of PLWHs and their families.

The majority of health workers reported not having a palliative care team at their health facilities, but this was inconsistently reported in the different facilities. The majority of health workers did not have any training related to palliative care for PLWHs. Most of health workers reported that regarded themselves as being “not knowledgeable” about the role of physiotherapy in palliative care of PLWHs.

Various factors such as the lack of skilled staff, lack of policy on palliative care, a lack of infrastructure (space for counselling) and the stigma around HIV/Aids were reported as obstacles in the provision of optimal palliative care. Interpretation of the results will be discussed in chapter five.



CHAPTER FIVE

DISCUSSION

5.1. INTRODUCTION

This chapter focuses on comparisons between the findings of the current study and those of related studies. A number of problems experienced by PLWHs as a result of the illness and their perceived palliative care needs are discussed in relation to similar studies. Met and unmet palliative care needs, including the preferred place to be looked after in terminal illness, are also discussed. The understanding of the concept of palliative care and the role of physiotherapy in palliative care for PLWHs are commented on. The need for palliative care for PLWHs, the provisions of palliative care for PLWHs and the impact of findings on both consumers (PLWHs) and health services are also investigated. Furthermore, attention is given to how amelioration of the impact of the findings pertaining to Rwanda can be achieved. Finally, a number of limitations of the study are highlighted.

5.2. RESPONSE RATE OF PARTICIPANTS IN THE STUDY

The response rate of 100% for PLWHs and 80% for health care providers is much higher than the general response rate from similar studies, which ranged between 54-63% (Kikule, 2003; Karus et al., 2004). This reflects the participants' willingness to narrate issues that concern their lives to any interested parties. This is a positive sign for further study in the field of palliative care for PLWHs, particularly in sub-Saharan countries, where such studies have not yet been conducted. Furthermore, response affirms the feasibility and practicalities of research in palliative care when an appropriate research method is used.

Other researchers have faced problems with study designs and response rate from PLWHs due to reasons such as early deaths, problems ethical dilemmas with recruitment and a low compliance rate for completion of questionnaires (McWhinney, Bass & Donner, 1994; Field, Clark, Corner & Davis, 2001). This study is a pioneer study in Rwanda and the participants' interests provide insights for further research in palliative care for PLWHs in Rwanda.

5.3. GENERAL FINDINGS RELATED TO DEMOGRAPHIC FACTORS

The general findings related to demographic factors of PLWHs include factors such as age, gender, and employment and income.

5.3.1. Age

The mean age of the participants who are living with HIV/Aids is relatively low (37.7 years). It confirms the high prevalence of HIV among youths and young adults from the age group of 15-45 years. One explanation is that at this particular age, individuals tend to be more sexually active, hence causing them to be at a high risk of HIV infection. Gwyther & Rawlson (2004) report that in South Africa, half of all infected adults are infected before 25 years of age, while the percentage of adults (aged 15-49 years) living with HIV/Aids is 20,1%. In addition, Kikule, (2003) in her study on palliative care needs for terminally ill people in urban areas in Uganda, reveals similar findings where the mean age was less than 50 years.

5.3.2. Gender

Worldwide, it is well known that the majority of PLWHs are women (UNAIDS, 2003). The participation of more females in this study supports this. The vulnerability of women to HIV/Aids is due to various factors such as premarital and extramarital sexual relations, resistance to requests for condom usage, the economic disempowerment of women and biological vulnerability (Gwyther & Rawlinson, 2004; Leclerc-Madlala, 2000; Doyal, 2000). The high percentage of women participation in this study could be the fact that at the time of the study women were the most participants attending hospitals and HIV clinics. In addition, in Rwanda, the 1994 genocide war also contributed to the spread of HIV due to the fact that many women were raped during genocide and half of the 3.2 % of women who reported being raped are now HIV (UNAIDS, 2001).

5.3.3. Employment and Income

There was a higher level of unemployment (including housewife) amongst PLWHs (67.2%) in the study. This is rather higher compared to the overall level of unemployment (64%) of the general Rwandan population reported by Schoppen et al. (2001). Butare Province had a highest level of unemployment of PLWHs compared to Kigali Province. This is explained by the fact that Butare province is more rural compare to Kigali Province, which is the capital city the country. It is likely that employment opportunities in Kigali province are many than Butare province.

The number of unemployed HIV/Aids participants is almost exactly the same as the national average. However, the unemployment amongst participants could likely be linked to HIV. The HIV virus weakens the body and thus could affect work performance; as a result PLWHs lose their jobs.

In a similar study conducted in Uganda, the findings revealed that 30% of PLWHs had lost their income due to their disease (Kikule, 2003). In addition, the USAID-Rwanda report (2003) supports the loss of income of PLWHs by saying that HIV/Aids will result in a loss of income for PLWHs, as well as a switch of household expenditures to health care costs and funeral and mourning costs. Although in this study the loss of income of PLWHs due to the disease was not explored, the findings of this study revealed that 29% of PLWHs with an income of Frw (5,000-20,000 = ~ R200-500) spend the same amount (5,000-20,000 = ~ R200-500) of their monthly income on medication. It is likely that most of their income is spent on medical expenditure. In addition, stigma and discrimination of PLWHs are amongst the contributing factors of unemployment, especially in African countries (UNAIDS, 2001). PLWHs might not be employed or might have to leave their jobs due to the attitudinal work environment, which discriminates and stigmatises them. As a result, PLWHs do not want to disclose their HIV status in order to protect their jobs. One participant reported that:

I do not want to disclose my HIV status now to my boss, because I do not want to lose my job. If I disclose my HIV status at work, I will be sacked from my job.

Income was an important determinant of access to medical care. This is supported by several studies which show that poor individuals or individuals with a low income were likely to lack a regular source of care as a result of financial problems.

Access to treatment was essentially controlled by the ability of the patient to pay (Karus et al., 2004; Kikule, 2003; Spence et al., 2004). Currently ARVs are available in many countries in sub-Saharan Africa. However, few patients can afford them (Gwyther & Rawlinson, 2004; Sepulveda et al., 2003; Spence et al., 2004). Although, in Rwanda, the ARVs are free of charge for PLWHs who have a CD4 cell count below 200/mm³, treatment for opportunistic infections is not free of charge. Hence access to treatment for opportunist infections and other conditions depends on patients' income.

This was confirmed by one of the HIV/Aids unit coordinators in the interview:

Drugs for treatment of opportunistic infections are very expensive; patients cannot afford them neither does the hospital always provide them.

Therefore, the findings of this study confirm that access to treatment depends on patients' income or ability to pay for it. Affordability will affect the QoL of PLWHs. Hence strategies to get access to treatment and drugs such as ARVs and drugs for opportunistic infections such as NIH, Cotrimoxazole, etc, are needed in order to enhance the QoL of PLWHs.

5.4. PROBLEMS EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS RELATED ILLNESS

Despite the efforts made by the Rwandan government with regard to HIV/ Aids care, PLWHs are still facing many problems as a result of the disease. Various problems were identified by PLWHs, although the predominant ones were financial problems, psychosocial problems, and pain and other physical symptoms. This conforms with studies conducted in Uganda and Kenya, where physical pain and financial and social problems appeared to be the most common problems faced by PLWHs as a result of the disease (Kikule, 2003; Grant et al., 2003).

In Rwanda, like in many African countries, poverty has affected the country and has led to poor health care, especially in the case of HIV/Aids where access to opioid or ARVs drugs are limited or non-existent and psychosocial support to PLWHs is very limited (GoR & William John Clinton Foundation, 2003). Depression, homelessness and lack of food represent patterns of psychosocial problems that PLWHs are faced with as a result of their illness. However, affordability of medication and psychosocial services dependent on the patients' income (Selwyn & Forstein, 2003). Needless to say, the government and health providers should develop a strategy such as expansion or availability of psychosocial centres to deal with psychological problems and social problems. Also income generating projects or activities should be encouraged so that PLWHs will be able to get a source of income to ease problems resulting from the disease.

5.5. PERCEIVED PALLIATIVE CARE NEEDS

Palliative care needs for PLWHs are multifaceted depending on many factors such as stage of the disease, the health infrastructure or system of each country and the socio-economic status of PLWHs.

The findings of the study related to palliative care needs are alarming, especially the need for financial assistance, medical care that include access to ARVs and treatment of opportunistic infections, and nutrition. There is a great concern regarding the economic status of PLWHs and the health system or infrastructure in place with regard to HIV/Aids.

Health workers, the HIV/Aids unit coordinators and PLWHs had similar perceptions of palliative care needs for PLWHs. Perceived palliative care needs identified were pain relief and management of symptoms; access to ARVs and opportunistic infection treatment; nutrition; HBC; financial assistance; housing; physiotherapy; access to HIV/Aids information; psychological support for both patients and their families; and spiritual counselling. However, the most frequently mentioned perceived palliative care needs for PLWHs were financial assistance, HBC, nutrition/food, pain relief and access to ARVs. The study findings have been supported by other studies across the globe (Beedham, 1995; Harding et al., 2003; Harding & Higginson, 2004; Grant et al., 2003; Karus et al., 2004; Kikule, 2003; Lau et al., 2003; Lasechinger et al., 2005; Sepulveda et al., 2003; Spence et al., 2004; Rani et al., 1997; WHO, 2002).

5.5.1. Financial assistance



The need for financial assistance in this study was mentioned more often than in other similar studies carried out in other countries (Karus et al., 2004; Lau et al., 2003; Rani et al., 1997; WHO, 2002). Only three participants reported that they have received financial support. This is because the majority of the Rwandan population lives below the poverty line. This was confirmed by the coordinator of the HIV/Aids unit at the centre for treatment and AIDS research at the national level.

HIV/Aids impoverishes PLWHs to a further degree. Patients tend to lose their income due to the chronic nature of the illness. A study on household expenditure by PLWHs in Rwanda showed that HIV seriously impairs the ability of the households to meet basic needs (Schneider et al., 2000). Poverty plays a big role in relation to the health infrastructures or system.

It has led to an insufficient provision of drugs for opportunistic infection, limited ARVs and other opioid drugs and limited psychosocial support to PLWHs. As a consequence the needs for PLWHs were still unmet.

5.5.2. Home-based care

The majority (62%) of PLWHs perceived HBC care as a palliative care need, but only 28% of PLWHs were visited by the HBC team on a regular basis. In similar study in Zimbabwe, One third of Aids patients needed HBC care, but the coverage was only 2-4% (Hansen et al., 1998). Although HBC was by far the most common model of palliative care provision in sub-Saharan Africa, the coverage was still low compared to the demand (Harding & Higginson, 2004). In Rwanda, the existing programmes on HBC are small-scale and relatively new, hence HBC for PLWHs still remain insufficient (Chandler et al., 2004).

5.5.3. Provision of food

Nutrition/food provision was perceived by most of participants (PLWHs and health care workers), as a palliative care need. Other studies in Rwanda have supported these findings (GoR, 2003). The reason for the need for food assistance to PLWHs is the fact that drugs such as ARVs weaken the bodies of PLWHs and it is no use continuing the treatment without food. One patient living with HIV/Aids explained:

If you are on ARVs you need to have sufficient food, because if you don't have food the drugs weaken you much more.



Studies have shown that micronutrient deficiencies are common in PLWHs and may accelerate the progression of HIV infection, which in turns leads to a worsening nutritional status (John et al., 1997; Normen et al., 2005; Ullrich et al., 1994 and Skurnick et al., 1996). In addition, estimates from food relief groups in Rwanda suggest that approximately 50% of PLWHs require some form of food assistance. However, only 20% of PLWHs had their need met with food assistance (USAID, 2004). Food support/assistance is paramount, boosting the immune system of PLWHs, which in turn will decelerate the progression of AIDS. As a consequence the quality of life of PLWHs will be enhanced.

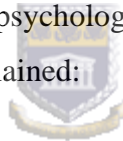
5.5.4. Medical care

Both PLWHs and health care workers perceived access to medical care as a major palliative care need. Most of PLWHs had pain and other symptoms. Only patients with HIV/Aids who had a low CD4 cell account below 200/mm³ could have access to ARVs free of charge. This is according to the national policy on anti-retroviral therapy (ART). However, there is no medical support for PLWHs whose CD4 cell count is above 200/mm³ despite their illness.

Although ARVs were free of charge for those who qualified, only 27,8% of PLWHs were on ARVs and antibiotics for the treatment of opportunistic infections. Such findings have been supported by other studies in Africa, which showed that access to ARVs was limited or non-existent (Harding et al., 2003; O'Neil et al., 2002; Sepulveda et al., 2002; Spence et al., 2004 and WHO, 2002). In addition, although 50,2% of PLWHs received treatment for pain, only 8% of PLWHs reported that the treatment helped. Thus the medical care needs, including pain relief and symptom control, are still unmet. Therefore, policy makers could set up poverty alleviation strategies to improve access and affordability of medical care/services for PLWHs and their families.

5.5.5. Psychological/emotional support

Psychological or emotional support was also perceived, as a palliative care need. The majority of PLWHs had psychological or emotional problems and most of them had received psychological support that helped a lot. This suggests that psychological/emotional needs of PLWHs were met to a certain extent. Although PLWHs had psychological/emotional support that helped, they also needed psychological support for their families. Franks et al. (2000) argues that palliative care should address psychological problems of not only patients, but also their families. One of the participants explained:



We also need counselling service, which will provide psychological support for my family (PLWHs).

Considering the Rwandan situation of the genocide war in 1994, where millions of people died and thousands of women were raped resulting in the high number of women who are HIV positive, it is understandable that psychological/emotional support is crucial to PLWHs and their families. Yet this need is still unmet.

5.5.6. Preferred place to be looked after in terminally illness phase

Both focus group discussion and questionnaires shows that hospital and HBC were the most preferred place to be looked after in terminal illness for PLWHs. However, the majority (67,2%) of PLWHs reported that the hospital was the preferred place. In contrast, studies conducted in other sub-Saharan countries such as Uganda, Kenya and others indicate that the preferred place to be looked after in the terminally ill phase is at home (Grant et al., 2003; Kikule, 2003; Sepulveda et al., 2003; Spence et al., 2004; WHO, 2002).

Such findings could be explained in countries where HBC is by far the best model for palliative care (Harding & Higginson, 2004). However, in Rwanda the situation is quite different. Very few HIV/Aids programmes provide HBC. The existing programmes on HBC are small-scale and relatively new (GoR, 2003). In addition, the findings of this study show that most of the participants (44%) were widows and lived alone or with their children, or a relative who was a survivor of the 1994 genocide war. Family members who were expected to take care of the patient may not be available due to the 1994 genocide war. As a result PLWHs prefer to be looked after in a hospital setting in their terminally ill phase. As one participant explained:

I would prefer to be looked after at the hospital than at home, because I do not have any one who can take care of me at home. I have lost all my family members during the 1994 genocide. My children are still too small to take care of me and I do not want to die in pain in front of them. (PLWHs)

Furthermore another participant added:

I would prefer to be looked after at the hospital in order to get proper medical care to reduce my pain till I die. (PLWHs)

In their study, Beedham & Wilson-Barnet (1995) supported these findings. They reported that patients indicate greater satisfaction with an Aids dedicated ward. The patients prefer to be treated in specialist wards and clinics, as there appears to be a higher degree of confidentiality and expertise. In addition, a study carried out in Ethiopia (WHO, 2002) shows that the majority (77%) of PLWHs prefer to be cared for in a hospital setting. The advantage of being looked after at the hospital is due to the kind of facility, which is better equipped and staffed to deal with the problem. Based on the findings of this study, this suggests that the development of strategies to improve the hospital palliative care is of great importance, since few participants in the study reported being visited by a palliative care team.

In addition, we could say that in Rwanda, strategies for HBC provision on a large scale with a comprehensive care (which include drug provision, pain and symptom control, nutrition, and financial assistance) are of great importance for meeting the needs of the patients at the end of their life, and helping them to die in dignity near their family members. In addition, the exact place for the provision of care at end of life or terminally ill phase is part and parcel of the palliative care programme.

5.6. HEALTH CARE SERVICES AVAILABLE TO MEET THE NEEDS OF PEOPLE LIVING WITH HIV/AIDS

The findings of this study indicate that there are both medical and psychosocial services or support available for PLWHs and their families. Health workers reported that information on HIV/Aids, voluntary counselling and testing (VCT), and Tri-therapy (ARVs) were the most common medical services available to PLWHs at their health facilities.

5.6.1. Medical care services

The majority of health workers reported that VCT and ART were the most common medical services available to PLWHs at their health facilities. Katz et al. (2000) support this, stating that in most countries, especially African countries, the priority of care for HIV/Aids care is medical care, which means the provision of ARVs and other drugs rather than other supportive services. Although the priority of care for PLWHs is of a medical nature, the findings of this study show that the majority (50,2%) of PLWHs had treatment for pain, but only 8% of PLWHs said that the treatment helped a lot. Pain relief and symptom management appear to be ineffective. Such findings have been supported by other studies, which showed that inadequate pain management is due to the lack of knowledge of health professionals on HIV/Aids and palliative care as well as a lack of access to essential analgesics or ARVs (Gwyther & Rawlson, 2004; O'Neill, et al., 2002). Consequently the medical care need with regard to pain and symptoms management was unmet.

5.6.2. Financial support services

The majority of health care workers (78%) indicated that financial assistance was offered to the family members of PLWHs at their health facilities. This contradicts with the patients' experiences, only three PLWHs reported that they had financial support.

Based on these findings we could say that financial need of PLWHs were still unmet. Similar findings have been supported by other studies (Kikule, 2003; ; Sepulveda et al., 2003; WHO, 2002). Although financial support was provided mostly by health facilities to the family members of PLWHs as reported by health workers, it is surprising that PLWHs were not the main beneficiaries of the service. Therefore, we could suggest that a further study of or investigation into channels of financial support and its impact on PLWHs and their family could be carried out for the sake of clarity and effectiveness of the services.

At present the financial assistance provided to family members of PLWHs do not seem to be contributing to solving financial problems or meeting the financial needs of PLWHs. In spite of the existence of financial assistance services to PLWHs, it is limited and insufficient. However, the overall pronounced level of poverty in Rwanda could explain the lack of or limited financial support to PLWHs. This suggests that health facilities in collaboration the Rwandan government and bilateral stakeholders should set up strategies for improvement of supportive services such as financial assistance and set up a policy on provision / accessibility of grants or financial aid to PLWHs and their families.

5.6.3. Palliative care programme

The majority of participants reported that they provided palliative care services. Palliative care education and hospital palliative care/in patient palliative care and financial assistance were the most common services provided by their health care facilities. This could be explained by a lack of information about what was available or the lack of accessibility of palliative care services by PLWHs, due to poor referral of PLWHs by health workers on necessary services. Therefore, each hospital should raise awareness on palliative care services available for PLWHs.



5.6.3.1. Palliative care team

Health workers were not consistent in their response with regards to existence of the palliative care team at their health facilities. There was a contradiction in responses. In general, over 50% of participants (health workers) reported that their health facilities did not have a palliative care team. This could be explained by the lack of a structure for palliative care and a limited understanding of palliative care. In addition, health workers were not consistent in their response with regard to the existence of a palliative care team at their health facilities. There was contradiction in responses. This suggests that either health workers who were part of the team knew about it and those who were not, did not know, or there is lack of information or structure regarding palliative care. Hence there is need for coordination in care and a need to raise awareness of the services or programmes within the health facilities.

This could help health workers to refer PLWHs to the appropriate services. Although some health facilities had a palliative care team, the care may not have been effective since most of the health workers did not have the same understanding of palliative care. One of the HIV/Aids unit coordinators explained further:

The service or the team is there, but it does not provide proper palliative care to Aids patients and their families. We still need a lot in order to provide a good care. While all of us have a team, we do not share the same understanding of palliative care.

In addition, in Rwanda, like in many African countries, palliative care for PLWHs is still a new concept and its development is not yet on the agenda for most of the governments (Sepulveda et al., 2003). Hence accessibility and availability of palliative is still an issue with regard to meeting palliative care needs for PLWHs.

5.6.3.2. Palliative care as a multidisciplinary team

Most of the health workers involved in HIV/Aids care were medical doctors, nurses and counsellors. Likewise, the palliative care team members were mostly nurses, medical doctors and counsellors. Similarly, O'Neil et al. (2002) reported that, in sub-Saharan Africa, palliative care team members or health workers involved in HIV/Aids care were mainly nurses, general practitioners/medical doctors, counsellors or social workers. By contrast, several other studies on palliative care indicate that medical professionals, including physiotherapists, occupational therapists, dieticians or nutritionists, outreach workers, a chaplain and an ethicist were members of the palliative care team (Selwyn et al., 2003; Williams, 1999).

A palliative care team should be a multidisciplinary team in order to cover all the aspects of QoL of patients and their families (Addington-Hall & Higginson, 2001; Harding & Higginson, 2004). This suggests that health facilities should establish multidisciplinary teams in palliative care.

5.6.4. Poverty in relation to palliative care provision

Rwanda is among the poorest countries worldwide and the 1994 genocide war has impoverished the country and its population. The majority of PLWHs had financial problems as result of the disease and this limited their access to medical care, food and other basic needs. Furthermore, the health system is also affected by poverty. Hence most of the health facilities do not have sufficient drugs and equipment to meet the demand of PLWHs who need palliative care. Harding et al. (2003) and Sepulveda et al. (2003) found that in many African countries limited access to medical care by PLWHs is linked to poverty.

Therefore, the government should take measures to improve the provision of palliative care by engaging with stakeholders and international funding agencies. Income generating projects for PLWHs would also help PLWHs to support themselves.

5.7. RESOURCES NEEDED TO PROVIDE OPTIMAL PALLIATIVE CARE

The majority of health workers reported that a 25% of increase in staff and a 50% increase in equipment are required to meet the palliative care needs of PLWHs and their families. In addition, a lack of skilled health workers, poor infrastructure, and a lack of funding and policy were also found to be major obstacles in providing optimal palliative care. Such findings have been supported by other studies (WHO 2002; Coughlan, 2004). One of the HIV/Aids unit coordinator explained further:

The service provided is very poor. Nothing has been done because of lack of skills and health workers. There is a need for an increase of skilled health workers in order to be able to deliver palliative care services. In addition, palliative care requires a lot of investment and equipment.

5.7.1. Training related to palliative care and HIV/Aids

Most of the health care workers (32,5%) held a Bachelor's degree as a highest level of education. In Rwanda, like in many other poor countries in Africa, the highest academic level offered in all tertiary institutions is a Bachelor's degree, especially in health sciences.

The majority (60%) of health workers did not have any training related to HIV/Aids and palliative care. The health sciences, and medicine or medical schools in particular, include only the medical aspect of palliative care for terminally ill patients. They do not include the psychosocial and spiritual aspects of palliative care.

Coordinators of HIV/AIDS units reported this. In addition, Gwyther & Rawlinson (2004) explain that most South African medical doctors receive little or no formal training in HIV/Aids care or palliative care and this has resulted in suboptimal and haphazard care. Health sciences should have a module on palliative care which includes all aspects of palliative care, including HIV/Aids care in order to improve the skills of health workers. This will help to meet patients' palliative care needs. The HIV/Aids unit coordinators support this:

I would suggest that palliative care be incorporated in the curriculum while medical professionals are being trained.

5.8. PHYSIOTHERAPY ROLE IN PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS (PLWHs)

The role of physiotherapy in palliative care is orientated to achieve the optimum QoL as perceived by patients, since it aims at facilitating the patient's ability to function with safety and independence in the face of diminishing resources (Boyce, 2004). The findings of this study indicate that over 50% of health workers said they were not knowledgeable about the role of physiotherapy in palliative care for PLWHs. However, all coordinators of HIV/Aids units interviewed said they were knowledgeable. This could be explained by the fact that physiotherapy in Rwanda is still at a developmental stage and lack of awareness / information on the role of physiotherapy in palliative care especially with PLWHs. This suggests that there is a need to increase the level of awareness of health workers on the role of physiotherapy in palliative care for PLWHs.

The role of physiotherapy in palliative care for PLWHs is further based on the finding that most of the present physical symptoms experienced by PLWHs include pain in the lower back, numbness of feet and hands, herpes zoster and neurological disorders.

In addition, recent studies show that many drugs used to treat opportunistic infections interact negatively with ARV drugs. Peripheral neuropathy is one of the major consequences of toxicities and complications of ARVs, and may affect adherence to medication, a major determinant of successful therapy (Anabwani and Navario, 2005; Gwyther and Rawlinson 2004; Selwyn et al., 2003). Therefore, neuropathic pain should be well managed by including non-opioid drugs and appropriate physiotherapy (Gwyther and Rawlinson, 2004).

5.8.1. Access to physiotherapy treatment

Despite the evidence of the importance of physiotherapy in management of neurological and non-neurological cases, the findings of this study indicate that only few (28%) health workers were "knowledgeable" about the role of physiotherapy in palliative care for PLWHs. In addition, the majority of PLWHs who had physical symptoms did not receive physiotherapy treatment. Such findings could be explained by the fact that in Rwanda, the number of the physiotherapists is low (Twizere, 2004).

Furthermore, the limited knowledge of health workers on the role of physiotherapy in palliative care could also affect the delivery of care especially when both health care providers and the patients do not know the importance and outcomes of physiotherapy treatment. It is therefore, important to raise the awareness of health providers on the role of physiotherapy in palliative care of PLWHs.

Physiotherapy is not yet part of the palliative care package of care provided to PLWHs in many health facilities. One of the HIV/Aids unit coordinators explains:

Patients with HIV/Aids do not receive physiotherapy treatment as part of palliative care. We do not have many physiotherapists in the country that could provide physiotherapy treatment.

In addition, since physiotherapy is not yet part of the palliative care, patients with HIV/Aids have to pay for it. Physiotherapy is costly in Rwanda. One of the PLWHs explains:

Physiotherapy is a real need for most of us. But the major problem is access. It is a separate service; we have to pay for it and we can not afford that



This suggests that, there is a need for inclusion of physiotherapy treatment in palliative care package of care for PLWHs like other care, such as VCT and ART. In addition, training of more physiotherapists is also required in order to accommodate the demands of PLWHs. However, training of physiotherapists should emphasise HIV/Aids and palliative care since physiotherapists have limited knowledge on pathology of the disease, ARVs and its side effects (Salati, 2004). Although this study did not explore the level of knowledge of physiotherapists in HIV/Aids and palliative care, it is likely that their knowledge is limited. Therefore, a study that evaluates the knowledge of physiotherapist in HIV/Aids and palliative care as well as their perceptions on their role in palliative care is needed.

In conclusion, in Rwanda like in many African countries, there is limited access to medical care. This includes physiotherapy, the availability of essential drugs such as ARVs, and other drugs for the treatment of pain and other symptoms, as well as psychosocial support for PLWHs. In addition, a lack of formal training on palliative care is also a major factor that contributes to poor, inappropriate or haphazard care.

Therefore, we could say medical and psychosocial needs for PLWHs are still unmet. There is a critical need for both human and financial resources. There is a need for a framework or policy on palliative care, as well as for training in palliative care.

5.9. IMPACT OF THE STUDY FINDINGS/LEVEL OF NEED FOR PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS

The findings of the current study are challenging, for health care professionals and policy makers alike. The majority of PLWHs had symptoms most of the time and had a limitation in performance in activities of daily living (ADL), which had led to loss of income and poverty. This affected their health status, including their psychological and emotional status and their social life. In addition, financial constraints and poverty have affected the health care provision, since most of the health facilities did not have sufficient drugs for treatment of opportunist infections, neither did they provide nutritional or financial support to PLWHs.

Although health care services, including palliative care programmes, were available to meet the needs of the PLWHs, most of the support or treatment provided did not help them meet all their needs, especially the psychosocial needs. In addition, most of the health care workers or providers reported that there is a need for an increase of both human resources and equipment to provide optimal palliative care and meet the needs of adults living with HIV/Aids.

The implications of the current study findings are threefold:

Firstly, the effect of unmet palliative care needs of PLWHs on their QoL. It is likely that the mortality rate of PLWHs will increase since most of the PLWHs do not receive adequate medical care and supportive services. In addition, PLWHs will die in pain and without dignity as a result of unmet palliative care needs.

Secondly, the effect on the socio-economic status of both the patients and the country. Access to medical care especially treatment for opportunist infections and physiotherapy treatment are expensive and depends on the ability of PLWHs to pay for it. As a result the medical care / medical expenditure and funeral costs will further drain the economic status of PLWHs and the economic status of the will be overstretched due to the burden of HIV/Aids.

The effect on the Rwandan provision of national health services provision. The increasing number of PLWHs, the limited number of skilled health workers to meet the demand of HIV/Aids patients and disparities in provision of palliative care will result in poor health services provision and equity of care.

Therefore, it is important for the Rwandan government; policy makers and the stakeholders to address vigorously the palliative care needs of adults living with HIV/Aids.

5.10. LIMITATIONS OF THE STUDY

This study is not free from limitations, which affect the generalization of the findings.

The following limitations are relevant:

- The study was not conducted in all 12 of the country's provinces and did not cover all health facilities with HIV/Aids care Units. Only two provinces, Kigali City and Butare, were included; although there were some patients from neighbouring provinces who came for medical care in Kigali and Butare, but the number was small to generalize to those provinces.
- The data was collected by means of a questionnaire, individual interviews and focus group discussions. No medical investigations or assessment tools for identifying symptoms were used. Symptoms were based on self-report. Although the patients' files were studied, most of them could not provide full medical information with regard to medication taken by these patients. Hence, the epidemiological approach was not fully utilised.
- The study did not categorise the participants (PLWHs) according to their stage of illness (i.e.4 stages of HIV) or have a control group for identification of needs. This was due to lack of time and the scope of a mini-thesis.
- The study did not include caregivers or family members of PLWHs. Their participation in the study could provide a broad picture on the palliative care needs of PLWHs. Given that, palliative care centres on both patients and the family as caregivers. In addition, views from stakeholders in charge of HIV/Aids Unit at the National level such as the National commission for HIV/Aids care and Control (CNLS), the National network of PLWHs, and donors could also deepen the understanding of a palliative care programme and its provision. This was due to lack of time and limited financial resources, and the scope of a mini-thesis.

5.11. SUMMARY

The discussion dealt with the major findings of the study. Similarities with other studies were found with regard to perceived palliative care needs, and met and unmet palliative care needs for PLWHs. The limitations of the study have also been described. The summary of the study, conclusion and recommendations based on the findings will be presented in the next chapter.



CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1. INTRODUCTION

In this chapter, a concise summary of the study is provided. The major issues in the study are provided in the conclusion, followed by proposed recommendations arising from the study.

6.2. SUMMARY

The purpose of this study was to investigate met and unmet palliative care needs for PLWHs in selected areas in Rwanda. The study identified the participants' palliative care needs and health care services presently available to meet these needs, determining to what extent palliative care needs are met.

The study was carried out on the premise that there had been an increase in the number of PLWHs, especially among youth and adults of the age group 15-49 years. This was partially as a result of the 1994 genocide war where, firstly, rape was used as a weapon, which explains the high rate of HIV infection among women, and secondly, a massive exile of the population to neighbouring countries where people living in refugee camps were at a high risk of HIV infection through unprotected sex and finally, the age group of 15-49 years is considered as sexually active group. In addition, the 1994 genocide war led to massive destruction of the infrastructure such as hospitals, which affected the socio-economic status of the country. The sudden increase of the prevalence of HIV/Aids in Rwanda had impacted on the health sector in terms of medical expenditure and health provision.

The nature of the disease has compromised the health status of PLWHs, resulting in various symptoms such as pain, vomiting, nausea, and neuromuscular conditions. In addition, the disease affects the psychosocial, the spiritual and financial well being of PLWHs. This has led to an extensive need for palliative care for PLWHs in Rwanda, like in many other African countries.

The findings of this study are alarming. Over 50% of adults living with HIV/Aids had symptoms most of the time and were limited in their ability to participate in activities of daily living such as bathing, dressing and cooking.

People who had been working, could not work any longer. This led to loss of jobs and income, contributing to a high level of unemployment. Pain was the most prevalent symptom (47%) among PLWHs; however, few of them received adequate treatment for pain relief.

Coordinators of HIV/Aids Units, health care workers and PLWHs all had the same perceptions of the most prevalent palliative care needs. These included the need for financial assistance, nutrition, management of pain and other symptoms, HBC, access to medical care for their families and treatment of opportunistic infections; as well as for psychological and emotional support for their families.

Most of the health facilities provided voluntary counselling and HIV testing (VCT), HIV/Aids information, and ARVs to PLWHs. However, nutrition/food, financial assistance and HBC were services, which were not provided to PLWHs in most of the health facilities. As a result, the financial needs, nutritional needs and needs for HBC were not met.

Although most of the PLWHs received treatment for pain and other physical symptoms, psychological/emotional support and financial support; only a number of people who had psychological/emotional support reported that it helped a lot in meeting their needs. As a result, medical care and financial needs were still unmet in respect of palliative care for PLWHs. Despite the satisfaction of PLWHs with regard to psychological/emotional support given to them, their families were neglected; yet the psychological support, in palliative care, needs to include the family.

In addition, the majority of health care workers involved in HIV/Aids care needed an increase of 50% of equipment and 25% of skilled health workers at their health facilities in order to meet palliative care needs of PLWHs. In spite of the establishment of a palliative care program or services in most of health facilities especially in tertiary or referral hospitals, the majority of health workers reported that the palliative care program did not have a structure and did not have a team. Furthermore, some health workers, involved in HIV/Aids care, working at the same health facility, did not know of the existence of the palliative care team. This has led to poor coordination in care delivery.

A lack of funding, a lack of infrastructure such as counselling centres, a lack of skilled health care workers, policy or guidelines on palliative care, as well as stigma and culture were obstacles that prevented the provision of optimal palliative care for PLWHs.

In addition, the majority of health workers indicated that they did not have adequate training on HIV/Aids and palliative care. Poor education or training in relation to HIV/Aids care and palliative care has contributed to the haphazard nature of care, especially in terms of symptom identification and management.

The majority of health workers indicated that they were not aware of the role of physiotherapy in palliative care, which aims at controlling pain and other physical symptoms and preventing disability. Furthermore, physiotherapy interventions were not yet part of the palliative care package of care provided to PLWHs. Most of the health facilities did not have enough physiotherapists; and the cost of physiotherapy was not affordable for the majority of PLWHs. Hence, physical conditions/problems experienced by PLWHs were unmet.

Finally, over 50% of adults living with HIV/Aids preferred to be looked after in hospital rather than at home in the terminally illness phase, due to various reasons such as a lack of proper care and medical care to reduce their pain while they are dying at home.

6.3. CONCLUSIONS

HIV/Aids remains a disease with several social consequences, and it primarily affects those who are already socially disadvantaged and poor. The litany of social woes that accompany infection include bereavement and loss of relationships, unemployment, disability, burdensome health care costs and demand, stigma and ostracism, and fear of premature death. Clearly, adults living with HIV/Aids in Rwanda face many problems as a result of the illness, especially those of a medical, psychosocial and financial nature.

This has raised the need for palliative care for PLWHs. In addition, the majority of patients had symptoms most of the time, and pain was the most prevalent symptom, which remained untreated. Furthermore, most of the perceived palliative care needs, such as nutrition, access to medical care, HBC, nutrition/food and financial assistance are rooted in poverty. This affects the country as a whole, and the health sector in particular. As a result, the above needs were unmet. Therefore, strategies on poverty alleviation such as micro financing projects or income generating activities for PLWHs would help PLWHs to meet their financial problems and will decrease government expenditure on medical cover for PLWHs.

Provision of comprehensive palliative care by health facilities that cover medical care and psychosocial, financial and spiritual needs of PLWHs would enhance the quality of care of PLWHs and meet their needs.

Palliative care in HIV/Aids is greatly affected by the extent to which the individual is established in a family. Attention to the needs and lives of families of HIV-infected individuals is paramount. Hence psychological/emotional support for family members is required.

Most of the health care facilities provided palliative care to PLWHs and their families. However, not all health care workers knew about the existence of these services or the support tailored to PLWHs and their families. As a consequence I could say that the unmet needs of PLWHs could be associated with a lack of information by PLWHs on supportive services, a lack of awareness by health care workers of the support services available, or a lack of coordination of care delivery, which points toward poor referral to the appropriate service. In addition, a multidisciplinary team was lacking or non-existent in most of the health facilities, particularly in primary health care and district hospitals. Therefore, policies and guidelines on palliative care for PLWHs are paramount for access and equity in palliative care.

Health promoting programmes should include an awareness of palliative care and the support services available, or of those offered by hospitals. In addition, the development of formal training on HIV/Aids care and palliative care for health professionals, together with the incorporation of a module on palliative care in the curriculum of students in the health sciences, would improve the skills of health professionals and prevent haphazard care. In addition, training of both physiotherapists and other health professional on the role of physiotherapy in palliative care especially for PLWHs is also required. This could enhance the quality of care and avoid haphazard care.

Special emphasis should be given to hospital-based palliative care, since the majority of PLWHs preferred to be looked after at the hospital in the terminally illness phase. However, the cost effectiveness of hospital based palliative should be taken into account since cost for providing hospital care was found to be higher than community based care. In addition, in order to enhance the HBC programme at large scale, trained family and community workers, including volunteers, should provide HBC to counteract the severe shortage of professional health care providers and limited funds.

Furthermore, the HBC programme should not only focus on counselling; it should include the provision of ARVs, opioid drugs and massage to alleviate pain, as well as nutritional support and financial assistance as part of the package of care, since the findings have showed that financial aid, nutrition and access to ARVs and other drugs were unmet palliative care needs.

Although this study was carried out in two provinces (Kigali and Butare) out of 12 provinces in the country, it is likely that the unmet and met palliative care needs of other PLWHs are similar, especially with regard to financial, medical, nutritional and HBC needs. This could be explained by the fact that the above-mentioned unmet palliative care needs are rooted in the poverty level of the country and its overall poor health infrastructure.

Taken as a whole, therefore, unmet palliative care needs were detrimental to the health status of adults living with HIV/Aids, as well as to the health care provision by health workers. If unmet palliative care needs are not met, this could compromise the QoL of adults living with HIV/Aids. Consequently, this would increase morbidity and mortality rates leading to an increase in health care expenditure of a country whose health budget is already overstrained.

6.4. RECOMMENDATIONS



Based on the findings of the study, recommendations are made in five parts:

6.4.1. Recommendations to the Rwandan Government

- There is an urgent need to carry out a health care needs assessment on palliative care for children and adults that will include all 12 provinces of the country and will give a more comprehensive picture of the need for palliative care with regard to PLWHs. Health needs assessments in palliative care require considerable attention in order to improve services and QoL of PLWHs.
- It is essential to integrate comprehensive palliative care with hospital- and home- based care programmes.
- The government policy on HIV/Aids care should emphasize access to and availability of drugs for treatment of opportunistic infections, including ARVs and other opioid drugs for pain relief, from primary health care and district hospitals.
- It is important to promote income generating projects or activities for PLWHs so that they can meet their financial needs that affect their well-being.

- It is advisable to collaborate with or set up a partnership with other African organisations on palliative care, such as the Hospice palliative care Africa association. A local palliative care network should be formed, as it is of fundamental importance to provide a focal point for the development of comprehensive palliative care services. These organizations, in collaboration with the National commission on HIV/Aids and control (CNLS) and Treatment and AIDS Care Centre (TRAC), should provide the structure for partnerships between PLWHs health professionals and the institutions such as hospitals, home-based care centres/hospices and universities for research purposes.

6.4.2. Ministry of Health

- To establish comprehensive palliative care which include all the components of care - medical, psychosocial, spiritual and educational. This will address unmet palliative care for PLWHs, including children.
- There is an expressed need for development of guidelines and implementation of policy on palliative care for adults living with HIV/Aids, from primary health care to tertiary level.
- It is essential to expand the HBC programme with links to health facilities, so that basic health services that include the provision of ARVs and other opioid drugs and social services, such as food and financial assistance, will form components of a home-based care policy.
- To engage communities and PLWHs as full and equal partners in the provision of palliative care and other response to the pandemic.
- A serious effort should be made to develop a policy or guidelines on access to grants, and on the provision of financial aid to PLWHs and their families.
- Psychosocial supportive services for family members of PLWHs should be developed without avail.
- Government should promote ongoing training of health professionals on palliative care and HIV/Aids. Emphasis should fall on pain and symptoms control.

6.4.3. Ministry of Education, Science, Technology and Scientific Research

- It is of paramount importance to establish formal training on palliative care and HIV/Aids for health professionals and to incorporate a module on comprehensive palliative care and HIV/Aids for students in the health sciences.

- To train more physiotherapists, since the number of physiotherapists is low compared to the demand of people requiring the service.

6.4.4. Recommendations for health professionals/ Hospital management

- A multidisciplinary palliative care team should be established to include all health care workers involved in HIV/Aids care.
- Patients and informal caregivers/family members must engage as part of the palliative care team, since palliative care is patient and family centred care.
- Health promotion programmes should provide HIV/Aids information with regard to prevention, nutrition, financial assistance and other support available for PLWHs.
- It is important that health workers provide training on essential or basic home- care to community workers, volunteers and family members, since most of the training are provided by NGOs.
- Physiotherapists should also work closely with home-based care team by providing skills to identify and manage neurological and non-neurological identification and management, such as massage and neuromuscular mobilization techniques.
- Physiotherapists should develop awareness programs on the role of physiotherapy in palliative care for PLWHs.



6.4.5. Recommendations for further research

- Ongoing clinical research and epidemiological studies must be encouraged and should include met and unmet palliative care studies of PLWHs as part of quality assurance.
- The use of a number of validated questionnaires is recommended for a more detailed assessment of symptoms presented by PLWHs.
- There is a critical need for research on the role of physiotherapy in palliative care of PLWHs in enhancing quality of life of PLWHs.
- There is an urgent need for evaluating the outcomes of physiotherapy interventions that could be helpful in palliative care by means of clinical trials and the establishment of a basic clinical performance for physiotherapist involved in HIV/Aids care.
- To investigate the accessibility to financial aid and the effectiveness of supportive services in enhancing QoL of PLWHs and their families.

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Appendix A

MET AND UNMET PALLIATIVE CARE NEEDS FOR PEOPLE LIVING WITH HIV/AIDS IN SELECTED AREAS IN RWANDA.

QUESTIONNAIRE: PEOPLE LIVING WITH HIV/AIDS

We are conducting a study to investigate palliative care needs of people living with HIV/Aids (PLWHs) in selected areas in Rwanda. You have been chosen to be part of the study and your contribution in filling in this questionnaire will be very important in order to improve the quality of care delivery and quality of life of people living with HIV/Aids in Rwanda. The information provided will be treated confidentially and your consent is a paramount.

NOTE:

Please do not write your name on the questionnaire. Select one or more response by using a tick in the box near your choice.

A. PERSONAL INFORMATION

1. How old were you on your last birthday? -----

2. Are you a female or male? 1. Female 2. Male



3. What is your Marital Status?
1. Single never married 3. Widowed
2. Married 4. Divorced


4. What is your highest level of Education?
1. No school attended
2. Primary
3. Secondary
4. Tertiary

5. What is your occupation?
1. Student
2. Housewife
3. Businessman
4. /Woman
5. Civil servant
6. Unemployed
7. Other

6. Which province is your usual place of residence? -----

Appendix A

B. HIV-RELATED HEALTH INFORMATION

7. For how long have you known you are HIV positive?
1. Less than 1 year
 2. 1-2 years
 3. 3-4 years
 4. 5-8 years
 5. Over 9 years
 5. I really cannot remember
8. Please indicate your current health status:
1. No symptoms
 2. Symptoms most of the time
 - 3 Symptoms regularly
 4. Advance stage of HIV
 5. Do not know
9. To what extent does your current health status limit your ability to take part in every day activities? e.g.: Feeding yourself, dressing yourself, bathing, etc.
1. Not at all
 2. A little
 3. A moderate amount
 4. Quite a bit
 5. A lot
- 
10. Have you ever been hospitalized due to the illness? If “Yes” proceed to question (X). If “No”, proceed to question XI.
1. Yes
 2. No
11. In the last year, how many times have you been hospitalized?
- | | | | |
|---|--|---|--|
| 0. None <input type="checkbox"/> | | | |
| 1. Once <input type="checkbox"/> | | 4. Four times <input type="checkbox"/> | |
| 2. Twice <input type="checkbox"/> | | 5. More than 4 times <input type="checkbox"/> | |
| 3. Three times <input type="checkbox"/> | | | |
12. Which of the following problems are you facing mainly as a result of your illness? **(Tick all that apply)**
- | | | | |
|--|--|---------------------------------------|--|
| 1. Pain <input type="checkbox"/> | | 5. Spiritual <input type="checkbox"/> | |
| 2. Emotional <input type="checkbox"/> | | 6. Social <input type="checkbox"/> | |
| 3. Vomiting <input type="checkbox"/> | | 7. Financial <input type="checkbox"/> | |
| 4. Stigmatization <input type="checkbox"/> | | 8. Other (specify) ----- | |

Appendix A

13. With regards to your illness, what do you perceive as palliative care needs? **(Tick all that apply)**

- 1. Pain management /relief
- 2. Nutrition/ Food provision
- 3. Physiotherapy management
- 4. Access to HIV/Aids information
- 5. Spiritual counselling
- 6. Access to Anti-retroviral drugs
- 7. Financial assistance
- 8. HIV/Aids counselling
- 9. Home-based care
- 10. Other (specify) -----

14. What kind of physical symptoms, do you have? **(Tick all that apply)**

- 1. Joint stiffness
- 2. Facial palsy
- 3. Facial paralysis
- 4. Hemiparesis
- 5. Paraparesis
- 6. Muscle soreness
- 7. Herpes zoster
- 8. Low back pain
- 9. Numbness of hands and feet
- 10. Tingling in hands and feet
- 11. Other (specify) -----

15. Have you received Physiotherapy? If “Yes” proceed to question (16-17). If “No” proceed to question (17).

- 1. Yes
- 2. No



16. Which kind of treatment? **(Tick all that apply)**

- 1. Mobilization
- 2. Massage
- 3. Electrotherapy
- 4. Chest-physiotherapy
- 5. Exercise-therapy
- 6. Other (Specify)-----

17. Which treatment helped you to improve your condition? **(Tick all that apply)**

- 1. Mobilization
- 2. Massage
- 3. Electrotherapy
- 4. Chest-physiotherapy
- 5. Exercise-therapy
- 6. Other (Specify)-----

18. If you are experiencing the following conditions, please answer this question.

| Conditions | Treatment received | | If “Yes” Specify Treatment received |
|----------------------------|--------------------|----|-------------------------------------|
| | YES | NO | |
| 1. Do you experience pain? | | | |

Appendix A

18.1.1. Did the treatment helped in relieving your pain?

- 1.Treatment did not help
- 2.Treatment helped a little
- 3.Treatment helped quite a lot
- 4.Treatment helped a lot

| Conditions | Treatment or support received | | If “Yes” Specify Treatment or support received |
|--|-------------------------------|----|--|
| | YES | NO | |
| 2.Do you experience psychological or emotional problems? | | | |

18.2.1. Did the treatment or support helped?

- 1.Treatment did not help
- 2.Treatment helped a little
- 3.Treatment helped quite a lot
- 4.Treatment helped a lot

| Conditions | Support received | | If “Yes” Specify support received |
|---|------------------|----|-----------------------------------|
| | YES | NO | |
| 3.Do you experience financial problems? | | | |

18.3.1. Did the treatment or support helped?

- 1.Treatment did not help
- 2.Treatment helped a little
- 3.Treatment helped quite a lot
- 4.Treatment helped a lot

C. INFORMATION AND SUPPORT SERVICES

1. Roughly what is your monthly income?

- 1: Less than Frw 5.000
- 2: Frw 5.000 – 20.000
- 3: Frw 30.000 – 50.000
- 4: Frw 60.000 – 100.000
- 5: Over Frw 100.000

Appendix A

2. Roughly what is your monthly expenditure on treatment? _____

- 1: Frw 5.000 – 10.000
- 2: Frw 15.000 – 20.000
- 3: Frw 25.000 – 30.000
- 4: Over Frw 30.000

5. What type of medication are you currently using? **(Tick all that apply)**

- 1. Anti-Retroviral drugs
- 2. Antibiotics (Prophylaxes)
- 3. Herbal medicines
- 4. Both Western medicines and Herbal
- 5. None

6. If none, what are the reasons that your are not on medication?

7. Do you have people who visit you regularly being at home or admitted?

- 1. Yes
- 2. No

8. If yes, who are they? (Tick all that apply?)

- 1. Medical Doctor
- 2. Friends from neighbourhood
- 3. Relatives
- 4. Nurse
- 5. Social worker
- 6. Counsellor
- 7. Religious leaders
- 8. Physiotherapist
- 9. Other (Specify)-----

9. Where do they come from? (Tick all that apply?)

- 1. Home based care team
- 2. Hospital –based Palliative care team
- 3. Church
- 4. Other (Specify)-----



If a Home care team has visited you, please proceed to questions 10. If a Hospital-based Palliative has visited you care team, please proceed to question 11. Tick all that apply

10. How has the home-based care team helped you?

- 1. Providing drugs
- 2. Counselling
- 3. Providing food
- 4. Financially
- 5. Providing Massage
- 6. Preparing my will
- 7. Other (please specify)

11. How has the hospital based palliative care team helped you?

- 1. Providing drugs
- 2. Counselling
- 3. Providing food
- 4. Financially
- 5. Providing Massage
- 6. Other (please specify)

Appendix A

If a Home based care team or a Hospital-based Palliative has not yet visited you, please proceed to questions 12. Tick all that apply

12. How would like to be helped by a home care team/ hospital-based palliative care team in order to meet your needs?

13. Where do you prefer to be looked after in terminally ill phase?

- 1. Home
- 2. Hospital
- 3. Home based care centre
- 4. I really do not mind where
- 5. Other (please specify)

14. Give reasons for your answer

THANK YOU FOR YOUR PARTICIAPTION



Appendix B

MET AND UNMET PALLIATIVE CARE NEEDS OF PEOPLE LIVING WITH HIV/AIDS IN SELECTED AREAS IN RWANDA.

QUESTIONNAIRE: HEALTH WORKERS INVOLVED IN HIV/AIDS CARE

We are conducting a study to investigate met and unmet palliative care needs of people living with HIV/Aids in selected areas of Rwanda. Your institution has been chosen to be part of the study and your contribution in filling in this questionnaire will be very important in order to improve the quality of care delivery and quality of life of people living with HIV/Aids in Rwanda. The information provided will be treated confidentially.

NOTE:

Please do not write your name on the questionnaire. Select one or more response by using a tick [X] in the box near your choice.

Please specify your work setting:

- I. Health centre
- II. District Hospital
- III. Referral hospital



A. PERSONAL INFORMATION

1. How old were you on the last birthday? -----

2. Are you a female or male? 1. Female 2. Male

3. What is the highest level of education you have completed?

- 1. Ao
- 2. A1
- 3. A2
- 4. A3
- 5. Other (specify) -----

4. What is your qualification?

- 1. Nurse
- 2. Physician/Medical doctor
- 3. Physiotherapist
- 4. Counsellor
- 5. Dietetician
- 6. Occupational therapist
- 7. Social worker
- 8. Psychologist
- 9. Other (Specify)-----

Appendix B

B. INFORMATION ON FACILITIES/SERVICES PROVIDED

6. Please indicate your main work setting / section : (Tick all that apply)

- 1. Consultation
- 2. Inpatient
- 3. Home- based care
- 4. Hospital-Palliative care service
- 5. Other (specify) -----

7. Which of the following people are your clientele (Tick all that apply):

- 1. 0-14 years
- 2. 15-29 years
- 3. 30-44 years
- 4. 45-59 years
- 5. 60 years and above

8. Approximately how many living with HIV/Aids patients do you have in the past three months?

- 1. 0-5
- 2. 6-10
- 3. 11-15
- 4. 16-20
- 5. 21-30
- 5. 31-40
- 6. >40



9. Approximately how many patients who are terminally ill with AIDS in the past three months?

- 1. 0-5
- 2. 6-10
- 3. 11-15
- 4. 16-20
- 5. 21-30
- 6. >40

10. Does your facility have a palliative care team?

- 1. Yes
- 2. No

11. Are you a member of Palliative care team?

- 1. Yes
- 2. No

If “Yes”, please proceed to question 12, if “No”, please proceed to question 13?

Appendix B

12. Who you work with? **Tick all that apply**

- | | | |
|--------------------|--------------------------|-------------------------|
| 1. Nurse | <input type="checkbox"/> | 6. Other (specify)----- |
| 2. Physiotherapist | <input type="checkbox"/> | |
| 3. Physician | <input type="checkbox"/> | |
| 4. Psychologist | <input type="checkbox"/> | |
| 5. Social Workers | <input type="checkbox"/> | |
| 6. Volunteers | <input type="checkbox"/> | |

13. Please indicate services provided by your palliative care programs

- | | | | |
|--|--------------------------|----------------------|--------------------------|
| 1. Palliative care education | <input type="checkbox"/> | 6. Financial support | <input type="checkbox"/> |
| 2. Bereavement support | <input type="checkbox"/> | 7. Legal support | <input type="checkbox"/> |
| 3. In –patient-hospital (No specific Unit) | <input type="checkbox"/> | | |
| 4. Home - based care | <input type="checkbox"/> | | |
| 5. In-Hospital (Palliative care unit) | <input type="checkbox"/> | | |

14. What care/service do you provide for PLHWs in your facility? **(Tick all that apply)**

- | | | | |
|-------------------------|--------------------------|--------------------------|--------------------------|
| 1. Counseling | <input type="checkbox"/> | 8. Nursing care | <input type="checkbox"/> |
| 2. Bereavement support | <input type="checkbox"/> | 10. Tri-therapy/ARVs | <input type="checkbox"/> |
| 3. Financial | <input type="checkbox"/> | 11. Other (specify)----- | |
| 4. Home based care | <input type="checkbox"/> | | |
| 5. HIV/AIDS information | <input type="checkbox"/> | | |
| 6. VCT | <input type="checkbox"/> | | |
| 7. Nutrition | <input type="checkbox"/> | | |

15. What care/service do you provide for the family of PLHWs in your facility? **(Tick all that apply)**

- | | |
|-------------------------|--------------------------|
| 1. Counseling | <input type="checkbox"/> |
| 2. Financial support. | <input type="checkbox"/> |
| 3. HIV/AIDS information | <input type="checkbox"/> |
| 4. VCT | <input type="checkbox"/> |
| 5. Nutrition | <input type="checkbox"/> |
| 6. Other (specify)----- | |

16. At your facility/department do you have staff to meet palliative care demand/needs of PLHWs?

1. Yes 2. No

17. If “No”, how much increase in staff would you need to meet those needs?

- | | |
|--------------------------|--------------------------|
| 1. 25% larger | <input type="checkbox"/> |
| 2. 50% larger | <input type="checkbox"/> |
| 3. 75% larger | <input type="checkbox"/> |
| 4. More than 100% larger | <input type="checkbox"/> |

Appendix B

18. At your department/facility do you have enough assets/equipment to meet the demands of PLWHs?

1. Yes 2. No

19. If “No”, how much increase does you need to meet those needs?

1. 25% larger
2. 50% larger
3. 75% larger
4. More than100% larger

C. INFORMATION RELATED TO HIV/AIDS AND PALLAITIVE CARE NEEDS

20. Did you receive any training related to HIV/AIDS?

1. Yes 2. No

If Yes, where and what type of training?



21. Did you receive formal palliative care training?

1. Yes 2.No

22. If Yes, at which level?

1. Ao 3. A2 5. Continuing learning
2.A1 4. A3 6.Other (Please describe)-----

23. Rating of HIV/Aids training

1. Totally inadequate
2. Generally Inadequate
3. Generally Adequate
4. Totally adequate

Appendix B

24. Rating of Palliative care training

- 1. Totally inadequate
- 2. Generally Inadequate
- 3. Generally Adequate
- 4. Totally adequate

25. Please indicate the degree difficulty for you in providing care for people living with HIV/Aids in the following areas. **(Circle one)**

- Not difficult 1**
- Quite difficult 2**
- No problem 3**
- Difficult 4**
- Very Difficult 5**

| | | | | | |
|---------------|---|---|---|---|---|
| Medical | 1 | 2 | 3 | 4 | 5 |
| Physical | 1 | 2 | 3 | 4 | 5 |
| Psychological | 1 | 2 | 3 | 4 | 5 |
| Social | 1 | 2 | 3 | 4 | 5 |
| Spiritual | 1 | 2 | 3 | 4 | 5 |
| Nutrition | 1 | 2 | 3 | 4 | 5 |

26. What is your opinion on the needs and obstacles that your department has to optimal palliative care in looking after HIV/Aids adult patients and their families? **(Tick all that apply)**

- 1. Lack of skills
- 2. Appropriate space for conducting counseling
- 3. Lack funding
- 4. Lack of policy
- 5. Stigmatization
- 6. Culture issues
- 7. Other (please indicate)-----

Appendix B

27. Do you feel that physiotherapy have a role to play in providing palliative care?

1. Yes 2.No

28. Please indicate the degree of knowledge which you feel physiotherapy have a role to play in providing palliative care for PLWHs?

1. Not knowledgeable
2. Slightly knowledgeable
3. Quite knowledgeable
4. Knowledgeable
5. Very knowledgeable

THANKS FOR YOUR PARTICIPATION!

