

**Palliative Care for People Living with HIV/AIDS in Uganda: An
Investigation of Patients and Caregivers' Outcome and Professional
Perspectives**

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Thesis submitted to The University of Nottingham for the degree of Doctor of
Philosophy

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ABSTRACT

Background: Although antiretroviral treatment is expanding in sub-Saharan Africa, the World Health Organization advocates for integration of palliative care with HAART because pain, other distressing symptoms and complex psychosocial challenges persist throughout the HIV trajectory. Palliative care improves the outcome for patients with HIV and may complement antiretroviral treatment by increasing adherence through better management of side effects from the treatment, providing patient and family-centred holistic care, and giving end-of-life care when necessary. However, integrating what have become two disciplines is challenging.

Aim: To study the implications for palliative care provision in the context of changing policy to universal access to HAART for people living with advanced AIDS (PLWA) in Uganda. Research questions addressed in the study included:

1. How do patients with advanced AIDS (stage III and IV) and with palliative care needs and their families experience care delivery and receipt over a period of 8 weeks?
2. How is the morphine roll-out programme among advanced AIDS patients operationalized in Uganda?
3. What are the challenges faced by health care workers involved in delivery and implementation of integrated palliative care for patients with advanced AIDS?
4. What are the views of key opinion leaders on development of palliative care policies in Uganda?

Methods: A mixed methods approach was employed. The study comprised of three phases.

In phase one, a consecutive sample of 30 newly enrolled patients advanced AIDS (stage III & IV) and their carers were recruited at Hospice Africa Uganda and followed up for 8 weeks. Qualitative interviews were conducted with patients and their carers at one time point and an outcome measure using African Palliative Care Association-Palliative Outcome Scale (APCA-POS) was used to assess changes in their experiences over 8 weeks, following access to palliative care. In phase two, 10 palliative care staff members participated in individual interviews and one focus group to explore the challenges they faced in delivering services to patients. Phase three explored, by the use of interviews with 7 key stakeholders, the broader context of palliative care policy development and opinions about key priorities for the future.

Findings: Out of 30 patients, 14 were male and 16 were female. They ranged in age from 18-60 years. The majority of patients were bed-ridden and experienced distressing symptoms related to advanced AIDS and AIDS-defining cancers which necessitated timely palliative care intervention. The key findings of the study relate to

the range of physical symptoms experienced by patients and the psychosocial challenges of disclosure and stigma encountered by patients and their families against a backdrop of profound poverty. Palliative care staff indicated two categories which broadly covered the challenges of palliative care delivery to PLWA in Uganda: service-linked and provider-linked challenges. Palliative health care staff and key stakeholders identified strategies to respond to palliative care needs for PLWA across four dimensions: a) partnerships or networking together with stakeholders; b) improving palliative care education; c) raising awareness of palliative care among communities and health care workers; d) advocacy and policies which support and strengthen initiation and expansion of palliative care services to PLWA, including the availability of morphine.

Conclusion: The study shows the paramount importance of drawing on patients' and carers' experiences and concerns to shape models of African palliative care. Both palliative care staff and key informants' perspectives highlight successes, barriers and important lessons for palliative care service delivery in Uganda. These lessons have several implications across the dimensions of practice, education, policy and research. Palliative care staff need to work with several key players or stakeholders to address the many psychosocial issues affecting PLWA including support during treatment. The study indicates the need to translate government policies on palliative care into action.

ACKNOWLEDGMENTS

Thanks to God Almighty who blessed me with an opportunity and guidance to carry out this research. I thank God for giving me the strength and guidance I needed at each stage of my work. There are many people who have contributed to the completion of this thesis. It is pleasure to thank all of them.

It is difficult to overstate my gratitude to my supervisors. This thesis would not have been possible if it were not for their constant guidance and invaluable support throughout my study at The University of Nottingham. First and foremost, I am deeply indebted to my supervisor: Prof Jane Seymour for her enthusiasm, inspiration and great support throughout and efforts in providing critical comments which not only stimulated my intrinsic motivation to work hard but also develop my own intellectual interests as well as research capabilities. I owe my deepest gratitude to her for effectively mediating timely feedback and providing excellent environment to share experiences during supervision meetings. I learnt 'how to care' having been a research student of Prof Jane Seymour. Equally, I am heartily thankful to my co-supervisors Dr. Michael Watson (The University of Nottingham) and Dr. Richard Harding (Kings' College London) for their thoughtful insight in providing me with fruitful and constructive comments at every stage. Special thanks would not be enough for their patience, time and views in reading my thesis from the earlier version of drafts to date.

This thesis would not have been possible if it were not for participation of PLWA and their family members. For their acceptance, time and willingness to share their account or stories I express my gratitude and admiration.

I would also wish to thank more people who became involved when the project scaled up. In particular I would like to acknowledge my debt to all staff at Hospice Africa Uganda. Special thanks for all directors for supporting and facilitating my research in one way or the other. My sincere gratitude to the founder of Hospice Africa Uganda: Dr Ann Merriman for her time and support. Special thanks to Dr Jagwe for his useful advice and support before I started to collect the data. I would like to show my gratitude to Commission of health in the Ministry of Health, Uganda: Dr Jacinta Amandua for the tremendous support he gave me. Special thanks to staff at Mulago National Referral Hospital (palliative care unit) and Cancer Institute. I owe special gratitude to Dr Lydia Mpanga-Ssebuyira (Infectious Disease Institute-Mulago National & Referral Hospital), Dr Julia Downing, Dr Faith-Mwangi Powell, Dr. Dduku at APCA. I would like to show my gratitude to Mrs Elizabeth Ombeva (faculty staff, Makerere University-Nursing) & Charlotte (Manager, HIV/AIDS at HAU) for their instrumental support during data collection & translation.

Special thanks to Dr Catrin Evans, Dr Linda East for their role in bridging international collaborations which finally saw me join this University to study as well as their encouragement and support throughout my study here. I am indebted to all my sponsors for their financial support. Special thanks to Aga Khan University-East Africa and The University of Nottingham, School of Nursing for the scholarships. Special thanks to my fellow colleagues for their peer reviews, encouragements and support during my study.

Finally, I would like to thank my dear wife Fancy Too for her patience, encouragement and moral support. Special thanks to my daughter Favor Cherotich for her love & support throughout my study. To all my sisters, brother, friends and

relatives, many thanks for being there for me and for your love. To all those who were involved and I have not mentioned their names, please accept my special thanks.

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DEFINITIONS OF TERMS USED

Caregiver: Is an individual who is viewed by health professionals and usually by the cared for person as being the person primarily responsible for delivering the majority of care and support. The family care giver provides unpaid assistance to the care for person as a result of their kin relationship.

Palliative Health Care Workers: Are trained individuals from either medical or nursing backgrounds or the professions allied to medical. For the purpose of this proposal, they are responsible for the provision of specialist palliative care.

End-of-life care: This is the care given to those with advanced, progressive, incurable/illness to live as well as possible until they die. It attends to the supportive and palliative care needs of both patient and family. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

End of life is underpinned by

- An active and compassionate care to care that ensures respect and dignity of the patient and family
- Partnership in care between patient, family and health and social care professionals
- Regular and systematic assessment of patient/carer needs incorporating patient consent and at all times
- Anticipation and management of deterioration in patient's state of health and well-being
- Advance care planning in accordance with patient's preference
- Patient's about place of care and death
- Sensitivity to personal, cultural and spiritual beliefs and practices

- Effective coordination across of care across all teams and providers of care (in statutory, voluntary and independent sectors) who are involved in care of patient and family

ABBREVIATIONS

- **ACP-AIDS** Control Program
- **APCA-African Palliative Care Association**
- **ART-** Anti-Retroviral Therapy
- **ARV-** Anti-Retroviral
- **AZT-** Azidothymidine (also called Zidovudine), it belongs to the drugs known as nucleosides reverse transcriptase (NRTIs) first approved by US Food and drug administration in the year 1987.
- **HAART-** Highly Active Anti-Retroviral Therapy.
- **APCA African POS-** African Palliative Care Association – African Palliative Outcome Scale
- **APOS-** African Palliative Outcome Scale
- **APCA** African Palliative Care Association
- **CD4+ cells-** *cluster of differentiation 4*, is a glycoprotein expressed on the surface of T helper cells, regulatory T cells, monocytes, macrophages, and dendritic. CD4 cells are specialized cells that are a part of our immune system
- **CHWs-** Community Health Worker (s)
- **CPCC-** Clinical Palliative Care Course
- **DDD-** Daily Defined Dose
- **DHMT-** District Health Management Team
- **ENCOMPASS-** Ensuring Core Outcomes and Measuring Palliation in Sub-Saharan Africa
- **GDP-**Gross Domestic Product
- **IPC-**Integrated Palliative Care
- **JCRC-**Joint Clinical Research Centre
- **KS-**Kaposi's Sarcoma
- **MoH-** Ministry of Health
- **NGOs-** Non-Governmental Organizations

- **HAU-** Hospice Africa-Uganda
- **HSSP-** Health Sector Strategic Plan
- **HBC-** Home Based Care
- **PCS-**Palliative Care Staff
- **PCAU-**Palliative Care Association of Uganda
- **PEPFA-** President Bush's Emergency Plan for Aids Relief
- **PLWA-** People Living With HIV/AIDS
- **PLWHAs-** People Living With HIV/AIDS
- **PNFP-** Private-Not-For Profit
- **PFP-** Private-For-Profit
- **PHS-**Professional Health Staff
- **PTB-** Pulmonary Tuberculosis
- **POS-** Palliative Outcome Scale
- **TASO-**The AIDS Support Organization
- **UAC-**Uganda AIDS Commission
- **UDHS-** Uganda Demographic Health Survey
- **UNCST-** Uganda National Commission for Science and Technology
- **UNAIDS-** Joint United Nations Programme on HIV/AIDS
- **VCT-** Voluntary Counselling and Testing
- **WHO-** World Health Organization

PUBLICATION & PRESENTATIONS BASED ON THIS THESIS

Too W., Seymour J., Watson M., Harding R., (2010), Palliative Care for People Living with HIV/AIDS in Uganda: An investigation of Patients & Caregiver's Outcome and Professional Perspectives. Emotional Health in People with Cancer Conference, Lace Conference Centre, University of Liverpool, 21st April. (*Awarded prize for the best conference presentation*)

Too W., Seymour J., Watson M., Harding R., (2010), Palliative Care for People Living with HIV/AIDS in Uganda: Patients' & family care givers' experiences. 6th EAPC research congress - Glasgow, UK - 10 - 12 June 10
<http://www.eapcnet.eu/Corporate/Events/Researchpastcongresses/2010Glasgowreport/pptpresentations/tabid/752/Default.aspx> (published online on 1st September 2010)

PUBLICATION

Too W., Seymour J., Watson M., Harding R., (2010), Palliative Care for People Living with HIV/AIDS in Uganda: An investigation of Patients & Caregiver's Outcome and Professional Perspectives. *Palliative Medicine*, 24:S5, Abs. 539 (publications linked to the presentation in the 6th EAPC research congress-Glasgow).

CHAPTER ONE

1.0 INTRODUCTION

This research study examines and report findings about palliative care for people living with HIV/AIDS (PLWA) in Uganda with special focus on the experiences of patients living with advanced AIDS, their family caregivers as well as health professional perspectives. The study sought to address the following research questions and objectives:

1. How do patients with advanced AIDS (stages III and IV) and with palliative care needs and their families experience care delivery and receipt over a period of eight weeks?

- a) To access patients' and caregivers' accounts of living with HIV/AIDS.
- b) To report problems (if any) encountered by HIV/AIDS patients and caregiver(s) and how these problems change over time.
- c) To measure palliative care outcomes for HIV/AIDS patients and how they change over time.

2. How is the morphine roll-out programme among advanced HIV/AIDS patients operationalised in Uganda?

- a) To describe the processes and practices involved in the morphine roll-out programme among advanced HIV/AIDS patients in Uganda.

3. What are the challenges faced by health care workers involved in delivery and implementation of integrated palliative care for patients with advanced AIDS?

- a) To ascertain how health care workers seek to respond and address patients' and family caregivers' needs in the context of a resource-poor setting.
- b) To discern the obstacles and challenges faced by palliative health care workers involved in palliative care delivery to patients with advanced AIDS.
- c) To examine the views of palliative care workers on actions that could be taken to develop palliative care delivery in Uganda.

4. What are the views of key opinion leaders on development of palliative care policies in Uganda?

- a) To develop understanding of broader perspectives on, and the context of palliative care in Uganda.
- b) To examine expert views on how palliative care delivery could be improved in Uganda.

To provide a background and context to this study, I will briefly highlight the significance and importance of this research, including a general overview of the natural course of HIV/AIDS and its treatment modalities.

1.1 SIGNIFICANCE OF THIS RESEARCH STUDY

Although Highly Active Anti-Retroviral Treatment (HAART) is expanding in sub-Saharan Africa, the World Health Organisation (WHO) advocates for integration of palliative care with HAART because pain, other distressing symptoms, and complex psychosocial challenges continue to persist throughout the HIV trajectory (WHO, 2005). Palliative care improves the outcome for patients with HIV (Harding *et al.*, 2005), and may complement antiretroviral treatment by increasing adherence through better management of side effects from the treatment, providing patient and family-centred holistic care, and giving end-of-life care when necessary (Harding & Higginson, 2005). However, integrating what have become two disciplines is challenging (Harding *et al.*, 2005).

Development of palliative care for HIV/AIDS has been neglected in sub-Saharan Africa, yet 80% of patients in need of this type of care are HIV/AIDS patients (Sepulveda *et al.*, 2002). Recently Uganda has taken initiatives to integrate palliative care with care for patients with HIV/AIDS (Jagwe, 2008). However, HIV/AIDS poses unique and particular challenges to the implementation of palliative care (Merriman & Kaur, 2005).

While there is little evidence of integration of palliative care services into existing systems for the care and treatment of people with HIV/AIDS in Africa (Harding & Higginson, 2005), Uganda has made some progress in integrating palliative care provision with new services to deliver HAART (Jagwe & Merriman, 2007). However, despite a strong commitment to HIV care and support in Uganda, the rate of progress regarding the development of palliative care is slower when compared to other areas

of HIV treatment like HAART (Kayiita, 2002). Creating a palliative care infrastructure to enhance wider access and coverage for PLWA in Uganda is required for the success of palliative care provision to PLWA in Uganda (Kayiita, 2002). It is against this background that this study seeks to address challenges, opportunities and successes of implementation of integrated palliative care for PLWA in Uganda.

1.2 OVERVIEW OF NATURAL COURSE OF HIV/AIDS

The natural course of HIV/AIDS is precipitated when new host cells are invaded with HIV (Bullock & Rosendahl, 1992). The HIV virus continuously replicates itself using new host cells. Patients infected with HIV develop life-threatening infections and malignancies over time (Calles, 2008). When the viral load continues to increase, and CD4+ count is less than 200 cells/mm,³ the patient is said to have developed AIDS (WHO, 2005). In people living with AIDS, development of opportunistic infections is common and many other secondary infections occur due to a severely depressed immune system. When the viral load is very high and the CD4+ count is less than 50cells/mm³, death is imminent (Bullock & Rosendahl, 1992).

There are two types of HIV that cause AIDS: HIV-1 and HIV-2 (Calles, 2008); very little is known about HIV-2. Various sub-types of HIV-1 have been found in specific geographical areas and in specific high-risk groups. They are sub-types A, B, C, D, E and F. Sub-type A is mostly found in sub-Saharan Africa (Calles, 2008).

1.3 HIV/AIDS EPIDEMIOLOGICAL FACTS: GLOBAL, SUB-SAHARAN AND UGANDAN OVERVIEW

To start with, the following table shows the epidemiological facts on global estimates of PLWHA, new infections and deaths due to AIDS by the end of 2008. The following table describes epidemiological facts on HIV/AIDS globally.

Table 1.1 HIV/AIDS epidemiological facts

Global estimates for adults and children, 2008		
People living with HIV/AIDS	33.4 m	31.1-35.8 m
New infections in 2008	2.7 m	2.4-3.0 m
Deaths due to AIDS in 2008	2.0 m	1.7-2.4 m

An estimated two-thirds (76%) of people living with HIV/AIDS worldwide are in sub-Saharan Africa. In 2008 alone, there were 1.9 million newly-infected people in sub-Saharan Africa bringing the total to 2.7 million new infections in that year alone globally. Sub-Saharan Africa accounted for nearly three-quarters (72%) of AIDS-related deaths in 2008. It is estimated that 80 million AIDS-related deaths will occur in sub-Saharan Africa and Africa at large by 2025 (Volmink, Dare & Clark, 2005). Therefore, sub-Saharan Africa remains the region most heavily affected by HIV/AIDS globally (UNAIDS/WHO, 2009).

Whilst the rate of new HIV infections in the region (sub-Saharan Africa) had declined by the end of 2008, there has been a slight increase of people now living with HIV, partly because of longevity stemming from improved access to treatment (HAART). For instance, HIV prevalence declined from 5.8% in 2001 to 5.2% in 2008 (WHO/UNAIDS, 2009). By the end of 2008, adults and children accessing treatment (HAART) was 44%, yet five years earlier the regional treatment coverage was only 2%. There are now other implications with many PLWA now living longer with the improved access to HAART: there has to be accelerated efforts to address palliative care needs of the growing numbers of PLWA.

1.3.1 HIV/AIDS estimates in Uganda: Incidence and Prevalence

It is estimated that 1,101,317 people were living with HIV/AIDS in Uganda as of December 2008. Further to that, it is also estimated that 110,694 new HIV infections occurred countrywide. Approximately 61,306 people died from AIDS in 2008 (Ministry of Health, 2009). An epidemiology review indicates that the previously

heralded decline in HIV prevalence from a peak of 18% in 1992 to 6.1% in 2002 may have ended since there is stabilisation between 6.1-6.5% and even higher in some sites of Uganda. Sepulveda *et al.* (2003) report an increasing palliative care burden each year in Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe with about 610,000 people dying from HIV/AIDS yearly over 2003 and 2005 in these countries.

1.4 TREATMENT OF HIV/AIDS (ART and HAART)

With improved access to treatment, there has been a reduced death rate, which therefore means there is an increased number of PLWA (Mathew *et al.*, 2005; WHO, 2004). There has been a dramatic change in HIV/AIDS care, with a shift in the pattern of the trajectory of dying from HIV/AIDS. During the pre-HAART era HIV/AIDS was associated with a rapidly fatal course. However, with the advent of new therapies including HAART and an emphasis on the importance of treating opportunistic infections, HIV/AIDS has gradually become a chronic disease for some. There now needs to be a focus on how to care and support PLWA over longer periods of time, many of whom have long term palliative care needs. Having an understanding of development of HAART is worthwhile in order to reflect on how best to respond to the changing palliative care needs of PLWA. The following section briefly lays out the history of developments of therapies and treatment for PLWA over time.

When the AIDS epidemic was first recognised in early 1981 (WHO, 2003), the diagnosis meant death within a relatively short time frame. When Zidovudine (AZT) was introduced as an ART regime for HIV/AIDS, the virus soon adapted to the drug, making it ineffective over time (De Noon, 1998; WHO, 2003). New drugs were approved in the 1990s, which attacked the virus in different ways (Pieperl & Coffey,

2006). When these drugs were used together with AZT (as a combined therapy), the HIV virus was kept under control. This combined therapy is known as HAART (Highly Active Anti-Retroviral Therapy).

WHO (2004) now recommends standard antiretroviral therapy (ART), which comprises at least three drugs to suppress the HIV/AIDS virus and stops the progression of HIV/AIDS. HAART therefore means any potent combination of three or more anti-HIV drugs. Studies which have investigated the impact of HAART on HIV/AIDS report clinical improvement among PLWA on HAART (Belzer *et al.*, 1999; Kanabus, 2001; Mathew *et al.*, 2005).

Whilst the traditional biomedical paradigm and model of treatment has concentrated its efforts in the physical treatment of HIV/AIDS, the symptom management and end-of-life care for advanced AIDS patients has been neglected (Sepulveda *et al.*, 2002) and the focus has now turned to care and training on HAART despite the fact that use of HAART in treatment alone does not address psychosocial, emotional, and spiritual aspects; in essence, palliative care is under threat of marginalisation (Duran *et al.*, 2001; Merriman & Kaur, 2005; Roca *et al.*, 2000).

The following section examines the definition of palliative care and then sets out a knowledge base for this study in trying to answer the question: why do we need palliative care amongst PLWA.

1.5 PALLIATIVE CARE

This section is further divided into three. The first part describes the definition of palliative care. This is followed by a rationale explaining why palliative care amongst PLWA is important. The last part describes palliative care policies and developments in Uganda.

1.5.1 Definition of palliative care

According to the World Health Organisation, palliative care 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 (WHO, 2002). The WHO further states that palliative care:

- ‘provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications' (WHO, 2002).

There have been recommendations for palliative care in resource-poor countries following development of a knowledge base to initiate palliative care services in a resource-poor setting. In relation to palliative care for PLWA, it focuses on an integrated form of palliative care in such a manner that palliative care is interwoven with disease-modifying therapies using a multi-disciplinary approach. It focuses on quality of life and on patient- and family-centred care. It is important to understand the scope and different stages at which palliative care service delivery operates in resource-poor countries; this is described it below.

1.5.2 Why do we need palliative care among patients with advanced AIDS?

HIV/AIDS is still the leading cause of death among Ugandan adults age 15-49. It is a known fact that HAART is not a cure and has many side-effects (Cooper *et al.*, 2009; Preau *et al.*, 2007; Selwyn *et al.*, 2009). Many symptoms throughout the disease trajectory impact on quality of life (MacLean *et al.*, 2005; Murphy *et al.*, 2000; Proctor *et al.*, 1999; Shacham *et al.*, 2008), and there are psychosocial issues among PLWA which are commonly not addressed (Antelman *et al.*, 2001; Greef *et al.*, 2008; Kadowa & Nuwaala, 2009; Lee & Johann-Liang, 1999; Medley *et al.*, 2009; Otolok-

Tanga *et al.*, 2007; Painter, 2001). Patients with advanced AIDS (stages III and IV) have severe and multiple distressing symptoms mostly characterised by opportunistic infections and persistent pain (Shelburne *et al.*, 2002; WHO, 2006), which undoubtedly would benefit from palliative care.

Some studies have reported a high prevalence of pain and symptom distress in the HIV/AIDS trajectory and highlight that pain is often under-estimated in the course of AIDS progression (Breitbart, 1996; Harding, 2005; Larue *et al.*, 1997) and its treatment is often therefore neglected (Sepulveda *et al.*, 2002). Recent research reveals that the majority of people with advanced AIDS experience severe pain (Foley, 2005; Harding, 2004; Laure *et al.*, 1997; Merriman & Kaur, 2005). For example, in one study, over 70% of people with advanced AIDS were reported to have experienced severe pain (Foley, 2005). Additionally, even where HAART is available, patients still suffer difficult symptoms (Fantoni, 1996; Praill, 2008; Rechtl, 2002) and as a result it has been reported that palliative care is necessary to support current and planned antiretroviral therapy as it promotes adherence (Harding, 2004). Having described the background of this study and the need for palliative care for PLWA, the following part describes the palliative care policy and development of palliative care with special focus on Uganda.

1.5.3 Palliative care policy and development in Uganda

Uganda is the only country in Africa that has made palliative care an 'Essential Service' in its National Health Policy. It is one of the four countries in Africa

classified as ‘approaching integration’¹ in palliative care, utilising a community-based model approach of palliative care (Clark & Wright, 2006) and influenced by the activities of Hospice Africa Uganda (HAU)² which is seeking to influence the spread of palliative care in the resource-poor context of Africa. I refer to Table 1.2 showing policy initiatives relating to the development of integrated palliative care in Uganda.

¹ Critical mass of activities countrywide with a range of providers and service types. There is a broad awareness of palliative care. There is a measure of integration with mainstream service providers and impact on policy as well as established education centres with academic links and research undertaken (Clark & Wright, 2006).

² Hospice Africa Uganda (HAU) is an African model developed to facilitate the initiation and expansion of palliative care to cancer and HIV/AIDS in Africa. It is a model which demonstrates that palliative care is both affordable and appropriate in resource-poor settings in Africa (available in <http://hospiceafrica.org/>).

Table 1.2: Summary of policy initiatives and development in palliative care in Uganda

Policies and development of palliative care	Source
Palliative care first started in Uganda on 23 rd Sept 1993 after formerly registered as Hospice Africa, UK.	Merriman, 2002.
In 1998, HAU opened two branches: Mobile Hospice Mbarara (MHM) and Little Hospice Hoima (LHH).	Merriman, 2002.
April 2002, 18-month course training began: to train palliative care specialists (to prescribe) and offer palliative care services.	
National Strategic Framework for Expansion of HIV/AIDS Care-policy builds capacity for the provision of care, standardise the care, provide essential drugs and supplies (including morphine), advocate for and increase public awareness, strengthen physical infrastructure for comprehensive care of HIV-infected patients.	Kamya, 2003; MoH, 2004.
Policy on integration of clinical services in the health centre includes integration of palliative care services into health units is included.	Kamya, 2003; MoH, 2003; MoH, 2004.
The palliative care draft policy is incorporated into the Health Sector Strategic Plan 1 (HSSP), 2000–2005 as well as the current HSSP II, 2006–2011, which clearly states that palliative care is fully covered and currently all government centres should be availing palliative care.	Jagwe & Merriman 2007; Uganda UNGASS Progress report, 2009; UNAIDS/WHO/UNICEF, 2008.
Policy by the government which has widened opioid prescribers to include nurses to maximise coverage and expand services to reach 57% of the population of Ugandans who are rural-based.	Clark & Wright, 2006; Jagwe & Merriman, 2007; MoH, 2003.

Table 1.3 provides a summary of changing policies that affect the treatment of people with HIV/AIDS, which include universal access of HAART by 2010. The ‘all by 2010’ policy initiative is currently being implemented in Uganda. Hence, provision of palliative care is viewed and perceived to be delivered in the context of the changing policy of HIV/AIDS treatment: universal access of HAART. The table 1.3 below shows the WHO policies regarding HIV/AIDS treatment in Uganda

Table 1.3: WHO policies regarding HIV/AIDS treatment and impact in Uganda

Policy initiatives	Description	Progress and impact in Uganda
3 by 5 initiative	The World Health Organisation created the first global target for ARV treatment access in 2003. The “3 by 5” initiative called for 3 million people in developing countries to have access to treatment by the end of 2005, which meant meeting 50% of estimated need. http://www.who.int/hiv/mediacentre/news57/en/index.html	At the end of 2005 only 1.3 million (40% of target) people in low- and middle-income countries were receiving ARV medication By 2005, only three African nations – Botswana, Namibia and Uganda – met their 50% targets.
All by 2010	The “All by 2010 ” initiative sets out a goal of universal access to ARV treatment by the year 2010 (now revised to 2015) http://www.who.int/mediacentre/news/releases/2007/pr16/en/index.html	In June 2004, Uganda began to offer free HAART to all those who needed it. By 2006 it had achieved coverage of 56% (UNAIDS, 2006); 80% of coverage of those who need HAART is a common definition of universal access.

In conclusion, while Uganda’s Health Sector Strategic Plan 1 (HSSP 1) clearly states that all hospitals and Health Centres IV³ should be providing palliative care, and confirms that adequate stocks of appropriate medication and supplies for palliative care should be available (Jagwe & Merriman, 2007); this is not the case in most districts of Uganda, especially rural settings (Jagwe, 2008). However, the National Strategic Framework for Expansion of HIV/AIDS Care supports the aspiration for expansion and implementation of integrated palliative care (IPC) in many parts of Uganda through capacity building for palliative care in collaboration with stakeholders (Kamya, 2003).

³ In Uganda, health facilities are categorised under health centres II, III and IV, with health centre IV providing comprehensive services and being spread throughout Uganda. In the hierarchy, Health Centre IV comes before the sub-District Hospital, then the District Hospital and finally Regional Referral Hospitals and the National Referral Hospital in that order.

1.6 UGANDA: HEALTH CARE SYSTEM

This section is divided into four parts. It begins with a brief description of Uganda as a country. It gives a general overview and understanding of Uganda. The second part describes the general context of health care service provision. The third part describes the specific context of palliative care provision to PLWA. It further highlights important features of palliative care practices and services. The fourth part describes the implementation strategy of palliative care provision.

1.6.1 Overview of Uganda

Uganda is located in East Africa with a population of 29.6 million (UBOS, 2009). It is a landlocked country in East Africa. Since independence in 1962, political leaders have had a series of leaderships, characterised by insecurities and instabilities. For instance Idi Amin came into power in an armed force way and had a military leadership which was ever more brutal, just before General Tito Okello who deposed him in 1985. The current president, Yoweri Kaguta Museveni of the National Resistance Army (NRA), entered into 'bush-war' to fight for leadership in 1986. Okello was then deposed from the presidency after ruling for only six months. In 1986, Yoweri Museveni came into power and became the president of the Republic of Uganda to the present day; however, there are rebel groups like the Federal Democratic Movement (FDC) and others who operate as opposition. Even to date there are still conflicts, especially in the Northern part which has displaced thousands of Ugandans and paralysed the economy of Northern Uganda.

Therefore, Uganda as a country has experienced political and social restructuring due to successive regimes of leadership. These experiences have had impacts in several ways. First it has complicated fights against HIV/AIDS, and also affected inflation rates in the country and economic growth of many Ugandans. Approximately 7 million Ugandans (26%) are now living in chronic poverty. Most Ugandans are predominantly rural-based and suffer inequalities in resource distribution. The following section describes the context of health care service provision to PLWA in Uganda (including palliative care).

1.6.2 General context of health care provision

1.6.2.1 Background

The National Health System (NHS) in Uganda constitutes structures made up of the public and the private sectors. The public sector includes all Government health facilities under the Ministry of Health (MoH), amongst others. The private health delivery system consists of Private Health Providers (PHPs), Private Not for Profit Providers (PNFPs) and the Traditional and Complimentary Medicine Practitioners (TCMPs) (MoH, 2010). The MoH provides leadership for the health sector. According to the Ministry of Health in Uganda, the provision of health services has been decentralised with health districts and sub-districts playing a key role in the delivery and management of health services. Unlike many other countries, in Uganda there is no ‘intermediate administrative level’ (province and region). The health care services are structured into National Referral Hospitals and Regional Referral Hospitals (RRHS), general hospitals; health centre (HC) IVs, HC III and HC II. The HC has no

physical structure, but has a team of people (Village Health Team) which works as a link between health facilities and the community.

National Referral Hospitals (NRHs) provide care for a population of 30 million people while Regional Referral Hospitals provide care for 2 million people and general hospitals provide care for 500,000 people. There are 56 public hospitals: 2 NRHs, 11 RRHs and 43 general hospitals. There are 42 PNFP and 4 PHP hospitals (MoH, 2010).

Health care service provision in Uganda is largely shaped by a number of factors. Whereas about 88% of the Ugandan population live in rural areas, 57% have not access to health care services including palliative care (Kikule, 2003; WHO/UNAIDS, 2000). This situation has affected PLWA in a number of ways.

First, patients do access health care services at the late-stage when their condition (HIV/AIDS) is advanced and are often managed as an in-patient (Koppler, 2007; Merriman, 2003). Given that the most common health care services are government facilities-hospitals and health centres⁴ the services offered are poor because of lack of facilities or inadequate facilities: lack of drugs and staff as well (DFID, 2004). These situations make it hard for patients to get quality health care service. Firstly, they have to resort to private health care providers who offer their services at relatively high costs, thus making health care services even harder to access (MoH, 2003). Secondly, nurses are reported to be the majority and the backbone of health care service serving mostly in rural areas where about 88% of Ugandans live (Walusimbi & Okonksy, 2004) but offer health care services under very poor conditions (DFID, 2004). Walusimbi and colleagues report lack of facilities, limited or inadequate resources and

⁴ Health centres are classified into five levels; Health centre I, II, III, IV.

shortages of health care affecting quality of health care service delivery. Other studies have pointed out that such circumstances affect quality of health care service delivery (DFID, 2004; Fournier *et al.*, 2007). The following part describes palliative care provision to PLWA in the light of the general health care systems in Uganda.

1.6.2.2 Palliative care services provision in Uganda

In Uganda, attempts are being made to graft palliative care into existing health service systems across a wide range of provision (Clark & Wright, 2006; Kamya, 2003; WHO, 2006) to allow concurrent pain and symptom management as well as HAART administration to AIDS patients (Dinat & Russel, 2003; Harding *et al.*, 2005; Selwyn, 2005; Selwyn, 2003). A recent report estimates that integrated palliative care is operational within 36 districts out of the total 56 districts (Jagwe, 2008; Kiwanuka, 2008), with HAU the main organisation providing palliative care training and facilitating the availability and administration of morphine.

In a wider context of palliative care service delivery in Uganda, the Ministry of Health has constituted a country palliative care team chaired by the Ministry of Health Commissioner for Clinical Services to oversee implementation of palliative care in a strategy which emphasises four pillars: drug provision, policies and advocacies, training, and implementation (Jagwe & Merriman, 2007). This strategy in essence is the public health approach/model which WHO advocates for in implementing palliative care service provision. The country team is responsible for establishment of guidelines and standards of palliative care within the national health policy (Jagwe &

Merriman, 2007). The network of this team has supported the public health approach in implementing palliative care service delivery.

The country palliative care team consists of:

- MoH: pharmacists and doctors
- Mildmay centre
- Hospice Africa Uganda
- TASO (The Aids Support Organisation)
- Uganda Cancer Institute
- The radiotherapy and surgical departments-mulago
- Makerere University
- Kitovu Mobile Care Centre
- The AIDS Control Programme-ACP/MoH
- WHO Representative's Office
- African Palliative Care Association

(Jagwe & Merriman, 2007)

Hospice Africa Uganda has adopted a public health strategy and is currently expanding its scope of palliative care to the terminally ill patients, especially patients with HIV/AIDS through district palliative care programmes. Through this approach it is hoped that the palliative care service will reach all those who are outside the Hospice Africa Uganda catchment area (Jagwe, 2009). However, the district palliative care programmes face challenges ranging from shortages of palliative care staff, health care workers with little palliative care knowledge and skill, and an unsupportive environment in which to implement palliative care.

1.6.2.3 How Hospice Africa Uganda delivers its services: models of palliative care delivery

Hospice Africa Uganda (HAU) has no in-patient facilities but offers its services through home-based care within a defined operational area. It was established to provide appropriate palliative care services to patients with cancer and/or HIV/AIDS and their families. It also provides training/palliative care education and is involved in advocacy work to influence policies relating to palliative care services in Uganda

HAU has three branches namely; Makindye (Kampala city-main), Little Hoima Hospice (LHH) located in Western Uganda and Mobile Hospice Mbarara (MHM) located in the South-Western Uganda. There are several models used at HAU to deliver palliative care services:

- Hospice: out-patients service and clinics based at health facilities like hospitals.
- Home visits to follow up of patients who are unable to access palliative care services due to their deteriorating condition
- Outreach using mobile units
- Day care services
- Community volunteer workers (partnerships with volunteers).

HAU works closely with local hospitals⁵ and other forms of health facilities to accept referrals of patients suffering from pain and symptoms. The main source of referral to

⁵ Mbarara, Hoima Regional Referral Hospital and Mulago National Referral Hospital

hospice (HAU) is self-referral. In addition, HIV treatment centres, community volunteer workers and HAU staff who are involved in community outreach also refer patients (HAU, 2008/2009).

HAU employs staff in different specialties and with various responsibilities. Apart from administrative staff, HAU has a wide range of expertise ranging from educationalists to clinicians. The following table 1.4 describes the staff working at HAU as at 2009.

Table 1.4 Characteristics of staff working at HAU at 2009

Category	Staff
Educationalists	<ul style="list-style-type: none"> • Palliative care nurse trainers • Palliative care nurse advocates • Distance learning diploma Tutors • Resource centre staff
Clinicians	<ul style="list-style-type: none"> • Community volunteer worker service staff • Children’s service staff • Clinical registrar • Specialist registrar • Medical officers • Clinical director • Health services staff/manager • Social workers • Palliative care nurses • Clinical managers • Pharmacists-dispensers • Occupational therapist
Program departments	<ul style="list-style-type: none"> • Quality assurance staff • Data management staff • Systems officer • Program director • Monitor and evaluation director

International programmes	<ul style="list-style-type: none"> • Director of policy and international programmes • Senior advisor, policy, medicine and advocacy • Clinical nurse trainer for international programmes
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Community volunteer workers (CVW) are trained to co-manage patients with hospice staff. CVW undergo a six day training which covers an overview of

- Fundamentals of palliative care
- HIV/AIDS and Cancer
- Basic aspects of nursing care (wound care, infection control measures, nutrition and general hygiene)
- End of life (death preparation, making will, bereavement process)
- Communication skills (counselling skills and keeping records)
- Emotional support to family members or carers
- Ethical issues in palliative care

After this training, CVW are able to identify and offer care for people needing palliative care in their own homes. They also offer support and advice to patients and their families including referring patients who are suffering from pain and distressing symptoms to HAU for palliative care. Thus, community volunteer workers (CVW) play a major role in delivery of palliative care services at HAU (Jack, 2009). In 2008/09 alone, CVW co-managed 250 patients with hospice (HAU, 2008/09).

To be a CVW, an individual must be a resident in a local community for at least one year and have basic literacy skills. One must also be selected by the community. By 2008, a total of 40 CVW were trained and now offer volunteering palliative care services at HAU (without pay but supplied with a bicycle and maintenance). By 2008,

it was approximated that about 120 patients receive ongoing care from CVW and approximately 46 patients were referred by CVWs to Hospice team (Jack, 2009). The details of services, inputs that patients receive at Hospice Africa are displayed in appendix X.

Given that about 57% of Ugandans cannot access any health worker coupled with shortages of doctors with nearly 80% of physicians approximated to be working in urban areas (Jack, 2009), community volunteer workers have tried to fill this gap.

1.6.2.4 Status of integration of palliative care

It is widely documented that there is integration of palliative care services in Uganda (UNAIDS, 2006; Jagwe & Merriman, 2007; UNAIDS/WHO, 2008; Kamya, 2003; MoH, 2004). However, this has largely remained at the level of policy (Jagwe & Merriman, 2007). It is expected that the policies on palliative care would result in palliative care provision throughout the nation through health care system to all those who need, yet that is not the case for most parts of Uganda.

To ascertain the status of integration of palliative care in Uganda; it is important to recognize the levels of integration. I will seek to explain the two levels of integration. First, integration of palliative care at policy level: in Uganda's Health Sector Strategic Plan 1 (HSSP) the need and aspiration to provide palliative care is clearly articulated (UNAIDS, 2006; Jagwe & Merriman, 2007; UNAIDS/WHO, 2008; Kamya, 2003; MoH, 2004) Second, at the practice level: it is observed that while policies spell out and support the aspirations of palliative care provision to all those who are in need, palliative care services are scarcely provided in government facilities or health care

facilities. Uganda's Health Sector Strategic Plan I (HSSP 1) clearly states that all hospitals and Health Centres IV⁶ should be providing palliative care. In addition, the policy confirms that government health facilities should have adequate stocks of appropriate medication and supplies for palliative care should be available (Jagwe and Merriman 2007), yet this is not the case in most districts of Uganda especially the rural setting (Jagwe 2008).

There is some evidence that palliative care is linked to HIV treatment in Uganda. However, this is limited to the palliative care model⁷ implemented in Western Uganda. The model has 121 centres spread over 4 districts in Masaka region. PLWA receive both palliative care services and HAART in those particular centres. More broadly, whilst commitment to HIV treatment (HAART) is strong, the pace of advancing integration of palliative care provision in context of HIV/AIDS treatment is slower (Kayiita, 2002; Jagwe, 2008). Health care workers in Uganda are yet to appreciate the need of linking palliative care to HAART treatment of HIV/AIDS because there are still misconceptions about the scope of palliative care which has resulted in an unsupportive attitude towards configuring care to link PLWA on treatment to palliative care (Dorothy & Harding, 2003; Harding, 2005, Jagwe & Merriman, 2007).

The chapters that follow examine these complex issues. The next chapter presents a review of the research literature relating to palliative care for PLWA. Chapter Three

⁶ In Uganda, health facilities are categorized under health centers II, III and IV, with health centre IV providing comprehensive services and spread throughout Uganda. Health centre IV follows sub-District then District Hospital and finally Regional Referral Hospitals & National Referral Hospital in that order.

⁷Kitovu palliative care model implemented by Kitovu mobile AIDS organization: started by medical missionaries and now run as NGO (faith-based). Available at <http://www.kitovumobile.org/>

presents the methodology and methods of the study. Chapter Four introduces briefly participants of the study. Chapter Five presents findings relating to the experiences of patients living with advanced AIDS and their family caregivers. Chapter Six presents an analysis of findings based on the administration among participants of the APCA (African Palliative Care Association) African palliative outcome scale (Harding *et al.*, 2010). Chapter Seven presents, firstly, the views of palliative health care workers on palliative care service delivery to PLWA at HAU; and secondly, it presents the views and opinion of key stakeholders of palliative care in Uganda. Chapter Eight is the concluding chapter and highlights the main findings and their implications for future research, policy and practice.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter gives insights into the most predominant palliative care needs in PWLA and critiques the body of existing research about palliative care for PLWA in sub-Saharan Africa and specifically in Uganda. It starts by providing a detailed overview of literature related to policy and strategic issues involved in palliative care service development in the resource-poor countries of Africa.

2.2 PALLIATIVE CARE DEVELOPMENT IN AFRICA: AN OVERVIEW

In Africa, palliative care initiatives have emerged and expand as ‘islands of excellence’, yet are an absent feature in most African countries’ national health policies (Clark & Wright, 2006). In the mapping of models and experiences of palliative care in Africa, Clark and Wright (2006) grouped the continent’s forty-seven countries into four categories in relation to their palliative care services: (1) no known hospice-palliative care activity; (2) countries with hospice and palliative care capacity-building activities; (3) countries with localised provision of hospice and palliative care; and (4) countries where hospice and palliative care activities are approaching integration with the wider public health system. The following shows the typology (characteristic activity within each category). The following table describes typology of hospice-palliative care services development in Africa.

Table 2.1 Typology of hospice-palliative care service development in Africa

No known activity	Capacity building	Localized provision	Approaching integration
	Presence of sensitised personnel. Expressions of interests with key organisations (e.g. APCA, Hospice information) Links established (international) with service providers Conference participation Visits to hospice-palliative care organisations Education and training (visiting teams) External training courses undertaken Preparation of a strategy for service development Lobbying of policy makers/health ministries	A range of capacity building activities but also: critical mass of activist in one or more locations Service established – often linked to home care Local awareness/support Source of funding established, though may be heavily donor-dependent and relatively isolated from one another, with little impact on wider health policy. Morphine available Some training undertaken by hospice organisation	Capacity building and localised activities but also: critical mass of activities countrywide Range of providers and service types Broad awareness of palliative care Measure of integration with mainstream service providers Impact on policy Established education centres Academic links Research undertaken National Association

Source: Clark and Wright (2006), review of hospice and palliative care development in Africa.

Home-based care (HBC) is by far the most common model of palliative care provision in sub-Saharan African countries, a resource-led decision by health care providers in response to provision of palliative care to increasing numbers of PLWA with limited resources (Harding & Higginson, 2004). Further, the HBC model has been reported to be flexible and offer culturally appropriate care and therefore this ensures sustainability of care among PLWA (Harding & Higginson, 2004). While this is the most common way of delivering holistic palliative care in sub-Saharan Africa, families and volunteers need to be trained on basic symptom control and health

workers in place to provide necessary back up (Harding & Higginson, 2004; Levy *et al.*, 2008; Russell & Schneider, 2000). In essence, it is now recognised that palliative care should be incorporated and work alongside and within other programmes (Levy *et al.*, 2008; Selwyn, 2003; Uys, 2000, 2001; WHO, 2004). Such recognition has led to the development and promotion of a public health strategy for palliative care, promoted by the WHO.

2.2.1 A public health strategy (PHS) for palliative care provision

Stjernsward and colleagues have argued that a public health approach to palliative care can underpin the development of cost-effective interventions that can reach everyone in the population (Stjernsward *et al.*, 2007). It is further reported that, for public health strategies to be effective, they must be incorporated by the governments into all levels of their health care systems and owned by community. The article spells out clear steps in implementation of palliative care using this strategy. Primary pillars advocated by WHO as part of Public Health Model are:

- 1) appropriate policies,
- 2) adequate drug availability,
- 3) education of health care workers and the public, and
- 4) implementation of palliative care services at all levels throughout society.

In addition to the above emphasis, WHO has since stressed consideration of culture, disease demographics, socio-demographics, socio-economics, and the health care

system of a given country in implementing palliative care services (Stjernsward, 2005). Therefore, it is impossible to develop a palliative care system that is separate from the existing health care system and social support. Stjernsward and colleagues (2007) advocate for palliative care experts spending 40-50% of their time educating and supporting other health care professionals and community support systems, in addition to providing consultation and direct patient/family care.

The strategy engages the community and clinical and administrative leaders together, which helps the community to see the need for palliative care for their patients and families. As a result, a system created from a movement within the community embracing the existing community support and health care system will be integrated as palliative care “from the people, for the people, by the people” (Ferris, 2001; Kumar, 2005; Stjernsward, 2005).

Wright (2004) provides a review of the methods which can be used as to assess health needs and review health services and programmes in relation to palliative care. Wright (2004) argues that the following questions should be posed: ‘Where are we and where do we want to go?’, ‘What is the current district (palliative) health care system?’, ‘What strategies can be used to improve the district palliative health care services?’, ‘What managerial support systems can be used to improve the district palliative health care system?’.

Pawinski (2006) argue that, to be effective, the public health approach must consider several country-specific factors. Whilst absence or presence of these factors can guide decision making about how best to introduce palliative care within a public health

approach so as to reach as many in the country as possible, it is also essential in assessing and monitoring existing palliative care services.

It is observed that, in resource-limited countries, HIV/AIDS are typically diagnosed very late in the course of a person's illness and so palliative care services may dominate the available services. In addition, this situation has further been worsened by the expensive nature of treatment regimens and the nature of the epidemic which has made it impractical and economically impossible for many of the patients with HIV/AIDS to be cared for at in-patient settings (Defilippi, 2003). Therefore, the primary focus of the palliative health care promotion has now been envisaged in community-based models, such as home-based care described above, which have become an important and widely-practised form of palliative health care (Uys, 2000). Successful implementation of palliative care in the community requires monitoring and evaluation as well as involvement and support of local communities in both planning and implementation of the home care programme, which is essential in terms of its acceptability and long-term sustainability (Defilippi, 2003).

2.3 REVIEW OF THE RESEARCH RELATING TO PALLIATIVE CARE FOR PLWHA

The research literature on palliative care for PLWAs was obtained by searching the databases. The following table displays the data bases used to search literature.

Table 2.2 Databases and search terms used

Data bases	Search terms
Science Direct (1990-2010) Medline (1990-2010) Embase (1990-2010) CINAHL (1990-2010) Grey literature <ul style="list-style-type: none">• WHO websites,• palliative care websites• Ministry of Health-Uganda• policy documents• hospice and palliative• palliative care websites	Palliative care, terminal care, people living with HIV/AIDS, Uganda, HIV/AIDS, patients with advanced AIDS, hospice care, end of life, sub-Saharan Africa

Search terms in table 2.2 guided identification of wide-range of sources used in this study. This search resulted in published materials on palliative care with focus on palliative care provision for PLWA. Based on my preliminary knowledge about palliative care, I was aware that there is little known before 1990. I therefore searched between 1990 and 2010. Grey literature included that drawn from the WHO and the Ministry of Health in Uganda websites.

2.3.1 Results of the Literature Review

Six themes emerged in the reviewed studies on palliative care in Uganda and sub-Saharan African countries. First, many studies have reported on experience of dying, quality of care at end of life and patient's unmet needs (Kikule, 2003; Memman & Binagwaho, 2004; Murray, Grant *et al.*, 2003; Sepulveda *et al.*, 2003; Spence,). Unmet physical needs such as pain and symptom relief, need for food, severe financial constraints on the family and caregivers, need for training for family caregivers, lack of psychosocial support and social isolation due to stigma attached to the diagnosis of HIV/AIDS (Spence, Memman & Binagwaho, 2004). Several recent studies indicate that majority of PLWHA in Africa require palliative care and that most palliative care needs for PLWA are still unmet (Grant *et al.*, 2003; Harding & Higginson 2004; Karus *et al.*, 2004; Kikule, 2003; Sepulveda *et al.*, 2002). Consistent with most African countries, the study in Uganda on people's preference in choosing where to die revealed that most people wish to die at home, close to ancestral burial grounds and where relatives can be there for them (Kikule, 2003).

Second and perhaps the most outstanding theme is pain and access to morphine. Pain was identified as a major issue in the studies and two of the papers from Uganda (Cartledge, 2004; Logie & Harding, 2005) addressed the issue of pain control alongside the availability of morphine within the country. Cartledge (2004) for instance suggests two-thirds of those attending palliative care services experience severe and prolonged pain before having access to pain relieving services. Logie and Harding (2005) later conducted an evaluation of morphine access in Uganda that was

implemented by HAU. Another survey of opioid availability in 12 African PEPFA⁸ countries (Uganda included) reported challenges in the supply and access of pain drugs, training/advocacy and government will to commit resources to palliative care (Harding, 2007). In one study (Uwimama & Struthers, 2007) using mixed methods in a descriptive cross-section, it was reported that over 50% had symptoms related to HIV/AIDS illness and a common symptom was pain. Similar needs assessments done in African countries have reported pain as the persistent challenge faced by PLWA (Agyarko, 2004; Baets, Anniek & Bulterys, 2007; Harding, *et al.*, 2003; Kikule, 2003; Logie & Harding, 2005; Selwyn, 2005). Despite these studies which document highly persistent and chronic pain amongst PLWA, there is still persistent under-recognition and under-treatment of pain (Selwyn, 2005). Other studies have documented contributory factors to persistent pain: poor understanding of palliative care among health providers as well as lack of trained human resource, inadequate funds for palliative care activities, lack of drugs for pain and poor access (Agyarko, 2004; Harding, 2005; Harding *et al.*, 2003; Logie & Harding, 2005).

In addition, one study by Harding (2004) using mixed methods to study terminally ill patients in sub-Saharan African countries unveiled pain control as the greatest challenge reported by PLWA who participated in the study. While there was government endorsement, the study revealed gaps in translating the government's commitment to the implementing and having the regulatory framework necessary for provision of palliative care. The study, however, recommended further research to understand the problems experienced by existing programmes.

⁸ US President's Emergency Plan for AIDS relief (PEPFA) is America's \$15 billion initiative to combat the global HIV/AIDS pandemic.

Dorothy and Harding (2003), in their multi-method study using interviews, key informants, direct observation and secondary data analysis to appraise morphine regulation, storage, prescribing and consumptions in Uganda, reported under-usage of morphine. This was largely due to professional fears coupled with deficient clinical skills which led to under-estimation of pain and complexity of follow-up patients in rural areas. It is debatable whether this habit of abandoning prescription by clinicians and mixed perceptions merits inquiry, especially given that Uganda still consumes only nine daily defined doses (DDD) of morphine as compared, for instance, to South Africa, which is the largest consumer (265) of DDD in the continent (Spencer, 2003). This study further unveiled the complexity in morphine regulation coupled with severe shortage of trained palliative care staff who are concentrated in hospices and cancer wards (in-patient), meaning that in practice palliative care was unavailable to many HIV/AIDS patients. Harding *et al.* (2005) in their survey study to identify current practices regarding palliative care implementation in 12 PEPFA countries (Uganda included) reported common factors hampering the supply of morphine ranging from central stores, unreliable stocks, and complex bureaucracy to having few prescribers. This study, however, failed to establish whether this changed with time.

A significant number of palliative care providers (64.5%) worked with ARV providers in integrated palliative care services offered to PLWA. The study recommended strengthening of the referral network and increasing opioid access. This study, however, lacked qualitative descriptions of experiences and views of palliative care providers to PLWA. A snap-shot description of palliative care in all 12 countries using questionnaires only may have encountered its limitations including taking into account changes with time, since it was done only once. Moreover, the self-completed

questionnaires approach that was used led to a decreased response rate. A more focused study that follows up the experiences of both health providers and PLWA receiving palliative care services would yield rich data.

The third theme is that the literature relates to the evaluation and validation of African-based tools for evaluation of provision of palliative care service delivery. One research study focused on the meta-evaluation of palliative care training in Uganda, specifically on learning needs and material design used for palliative care training (Downing, 2006), while another focused on validation of an African palliative care audit tool to measure outcome of pain (Powell, 2007). The scale is useful in African settings alongside the African Palliative Outcome Scale, which has been validated in Uganda to measure the effectiveness of palliative care providers (Harding *et al.*, 2010).

Fourth, other studies have concentrated on the need to have developed a model of palliative care services that is culturally sensitive and accessible. In these studies, it is reported that there is an overwhelming majority of Africans who currently endure progressive, life-threatening illness, while access to culturally appropriate holistic care (that includes effective pain management) is at best limited and at worst non-existent (Harding, 2005; Harding & Higginson 2004; Logie & Harding, 2005; Merriman & Kaur, 2005). These studies have recommended palliative care services for HIV/AIDS care, which are appropriate for diverse settings. Cognisant of this fact, Harding *et al.* (2005) surveyed 301 patients and reported that the majority of practices, models and strategies of delivering end-of-life in sub-Saharan Africa was provided at a home-based set-up. A Tanzanian needs assessment study reported that, while 83% of

terminally ill patients expressed a preference to be taken care of at home, 90% of their carers reported having no form of training (WHO, 2004).

The fifth theme in the literature concerns the need to develop national policies and strategies to support palliative care and ensure availability of drugs (Kikule, 2003; MoH, 2004; Murray *et al.*, 2003; Sepulveda *et al.*, 2003; WHO, 2004). These areas of policy and drug availability are two of the strategies of the WHO framework for palliative care within a public health framework.

The final theme in the literature relates to attempts to map or compare the status of palliative care in sub-Saharan African countries and to set out the lessons learnt from this comparison (Harding & Higginson, 2005; Harding *et al.*, 2003; Stewart *et al.*, 2003). Studies in palliative care in this area include systematic reviews and surveys. There are surveys of 48 programs from 14 countries African countries, including Uganda (Harding & Higginson, 2004; Harding *et al.*, 2003), followed by documentary evidence from 26 palliative care services (Harding *et al.*, 2005) informing the current practice and challenges related to expansion of palliative care in sub-Saharan Africa. The work of Harding *et al.* (2003), alongside Clark and Wright (2005), has played a key role in the mapping of palliative care in Uganda and sub-Saharan Africa more broadly.

Although it can be seen that there is an existing body of research in the area of palliative care in Uganda, the studies are characterised by some limitations. The majority have focused on terminally ill patients in general and not on patients with HIV/AIDS (Kikule, 2003; Murray *et al.*, 2003; Sepulveda *et al.*, 2003; Spence, Memman & Binagwaho, 2004). Further, they utilise cross-sectional approaches and

therefore have limitations in accounting for effects and changes over time. The changing needs of patients over time have been left unexplored, with one exception: a longitudinal study to ascertain the factors associated with missed appointments of AIDS patients on HAART in Lusaka, Zambia (Krebs *et al.*, 2008). In some studies reviewed, convenient samples or snowball samples were used, which limit representativeness. In addition, all needs assessment studies done in over five African countries have been based on the original work of Kikule (2003), to measure needs of terminally ill patients (Sepulveda, 2005). Little original research has been carried out in Uganda; the few existing studies do not adequately capture PLWA experiences of palliative care and tend to be based in urban settings, with rural areas unexplored (Kikule, 2003).

No single study has focused on palliative care for PLWA. The study done by Downing (2006) used African evaluation guidelines to evaluate the palliative care training in Uganda. Downing recommended the use of the APCA African POS (Harding *et al.*, 2010), which has been validated for use in Uganda to measure the impact of the palliative care programme on provision of palliative care. The tool was validated in 2007 and it is useful in resource-poor countries as it is cognisant of a resource-constrained setting.

2.4 CONCLUSION

Recent literature reveals a number of palliative care initiatives in Africa (WHO, 2004). Fundamentally, these initiatives have led to the development of a knowledge base about how affordable, appropriate and quality palliative care delivery can be

provided in resource-poor settings (Harding & Higginson, 2004; Jagwe, 2008; Merriman & Kaur, 2005). However, presently, there are existing gaps that need to be bridged.

This study was developed and built on the currently-existing gaps identified and hopes to contribute knowledge in the field of palliative care for PLWA. Using the findings of this study, it is hoped that it bridges the knowledge gaps as well contributing knowledge into the existing literature.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

This chapter provides a description of the methodological approach used and the data collection methods and procedures utilized in this study. Specific details provided include information about setting, sampling, analysis, ethics and dissemination.

The study which examines palliative care for people living with HIV/AIDS in Uganda was divided into three phases:

- **Phase one** – addressed the experiences of PLWA and their care givers using qualitative interviews conducted at one time point and an outcome measure, APCA-POS (Harding *et al.*, 2010) to assess changes in their experiences over time following access to palliative care.
- **Phase two** – used focus groups and interviews to access the views and experiences of palliative health care staff.
- **Phase three** - used interviews to gather the perspectives of key stakeholders in palliative care.

After this brief introduction, the main part of this chapter describes the three phases. For each phase, I will describe the methods in detail. However, before discussing the phases, I am going to set out the rationale underpinning the methodology.

3.2 CHOOSING THE RESEARCH METHODOLOGY: A RATIONALE

Designing a research study to measure the outcome of care given to PLWA over a period of time and to explore the experiences of patients, their family care givers, palliative care staff and key stakeholders required careful methodological consideration. In this study, mixed methods of data collection were applied with the aim of obtaining different but complementary data in order to better understand the research problems (Creswell & Clark, 2007; Creswell *et al.*, 2003). The design chosen was that in which a quantitative study was included within larger qualitative study; this approach was used because of the potential to expand quantitative results with qualitative data (Creswell & Clark, 2007).

According to Caracelli & Green (1997), there is a need to give full recognition to the full contribution of each methodology so as to consider a study as having used a mixed methods research design. On the one hand, quantitative research alone uncovers the relationship between variables, but does not explain the reason as to why such relationship exists (Rauscher & Greenfield, 2009). On the other hand, combining judiciously qualitative and quantitative data avoids the limitations of a single approach and assists in the interpretation or explanation of findings (Burgess, 2009; Polit & Hungler, 1995).

In relation to this study, quantitative data obtained on weekly basis (from the APCA POS tool) provided information about the outcomes of care for patients and care givers and enabled insight into changes of their experiences over a period of time.

This data provided descriptive statistics which were useful in characterizing sample participants. At the same time, qualitative interviews were carried out to highlight and provide more in depth information about patients' and caregivers experiences, and how staff and stakeholders experienced challenges in addressing their needs, which provided insights into some of the contextual factors giving rise to the APCA POS results.

A mixed methods approach was employed for this study with the aim of gaining insight into experiences of participants and the range of patients' symptoms and problems. Many authors argued that mixed methods employ deductive and inductive approach to generate theory or to test theory and hypotheses (Creswell & Clark, 2007; Green, 2007; Tashakkori & Teddlie, 2002, Creswell, 2009). However, this study employed mixed methods to primarily understand multiple perspectives on and dimensions of experiences, rather than seeking to establish patterns inductively or test theories and hypotheses (Creswell & Clark, 2007; Tashakkori & Teddlie, 2003; Creswell *et al.*, 2003).

3.3 STUDY DESIGN

Green (2007) suggests that guidelines for mixed methods are in development, with some disagreement about how to classify study designs. For instance, Tashakkori & Teddlie (2003) present mixed methods research literature with an overview of nearly 40 different types of study design. Similarly, Creswell & Plano Clark (2007) demonstrate classification of 12 types of mixed methods. In recent times, leading

mixed methods researchers have proposed that four key decisions are involved in choosing an appropriate mixed methods design (Creswell & Plano Clark, 2011; Creswell *et al.*, 2009, Onwuegbuzie & Leech, 2009 ; Onwuegbuzie & Johnson, 2004).

The four key decisions are as follows:

1. The level of interaction between the strands (Creswell & Plano Clark, 2011; Green, 2007).
2. The relative priority between the strands (Creswell *et al.*, 2009, Onwuegbuzie & Leech, 2009)
3. The timing of the strands (Creswell & Plano Clark, 2011, Onwuegbuzie & Johnson, 2004)
4. The procedure of mixing the strands (Creswell & Plano Clark, 2011).

The following part describes how these four key issues were taken into consideration in designing this study.

First, the study was designed and implemented in such a way that there was independent collection and analysis of qualitative and quantitative data in each phase. Green (2007) argues that there are two general options to describe level of interaction between strands: independent or interactive. Thus, the ‘independent’ study design involves quantitative and qualitative strands implemented in such a way that they are independent from each other but allow the researcher to mix the two strands when drawing conclusions at the end of the study (Creswell & Plano Clark, 2011).

In determining the priority of the quantitative and qualitative strands, it is suggested that researchers have to make decisions about the relative importance of the two

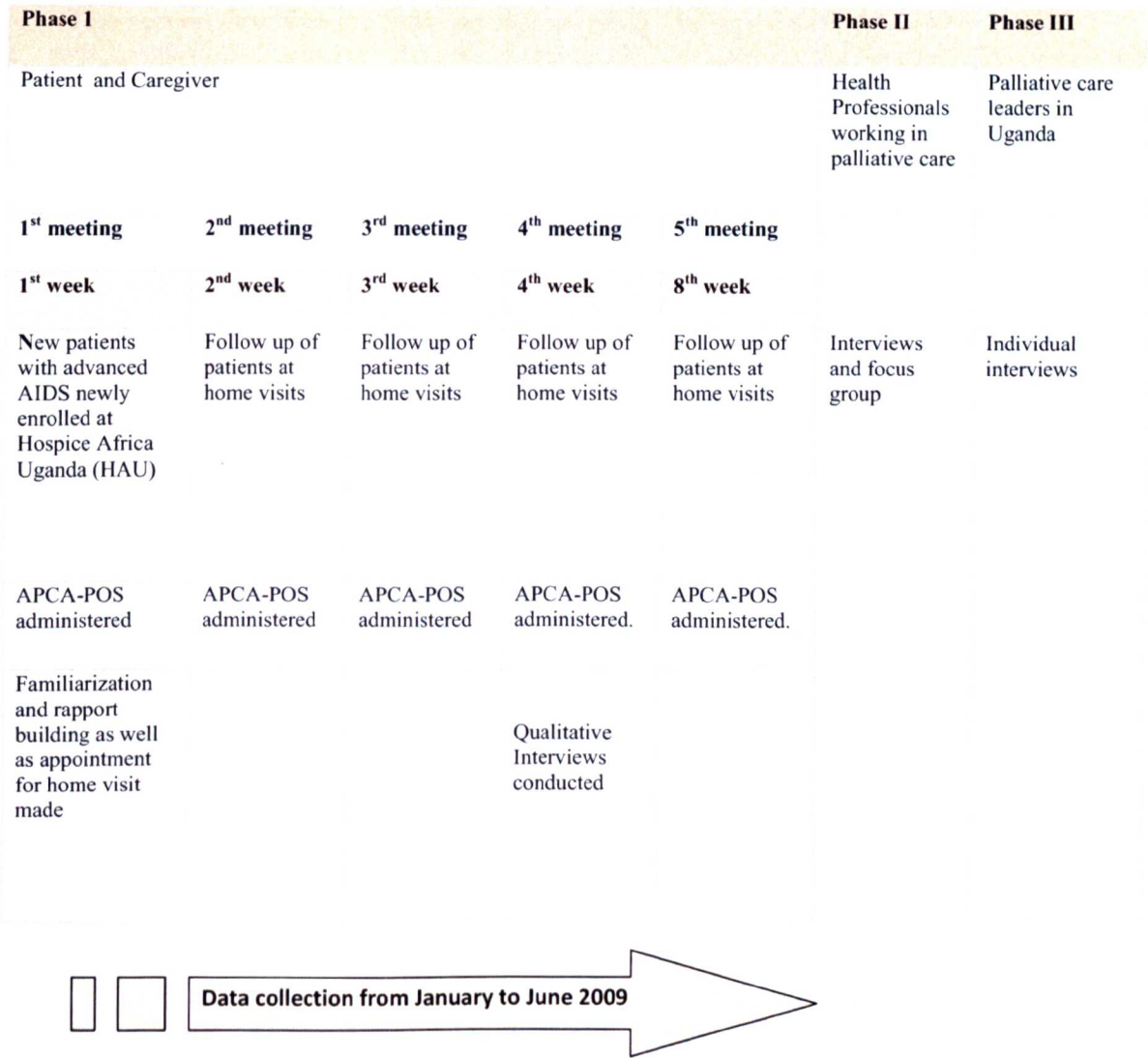
strands. In doing so, the researcher defines priority in terms of weighing emphasis given to each strand with three possible weighting options: equal status, quantitative priority or qualitative priority (Creswell *et al.*, 2009, Onwuegbuzie & Leech, 2009; Onwuegbuzie & Johnson, 2004). In my study, the emphasis was placed on the qualitative strand, which ran through all three phases.

Figure 3.1 shows the phases of the study and when the qualitative and quantitative aspects were undertaken. In phase 1, both qualitative and quantitative information was collected, whereas in phases 2 and 3 qualitative information only was collected. Timing within the mixed methods designs can be classified in three ways: concurrent, sequential and multiphase combination timing (Creswell & Plano Clark, 2011). According to this framework, this study utilized multiphase combination design combines the concurrent and sequential in one single mixed methods study.

Originally, the study was planned to have analysis of one data set (to inform) collection of second set of data. However, this process did not happen due to practical reasons. Despite this shortcoming, efforts were made to consider the dual findings of qualitative data and quantitative from phase one together when drawing inferences or conclusions. Creswell & Plano Clark (2011) have suggested four points of interface where mixing can occur: interpretation, data analysis, data collection and design. It is further suggested that where mixed methods keep the two strands independent, interpretation is the only step during which mixing occurs.

Schematically, I have described how the design was implemented in the study in the figure 3.1

Figure 3.1 design of the study and research activities



The following section describes the research process for the three phases used in this study.

3.4: PHASE ONE STUDY

3.4.1 Introduction

This section describes the study setting, sampling and recruitment of patients and care givers (family members) into the study. It also describes the process of accessing the participants-patients and family members. Descriptions of methods of data collections: interviews from APCA African POS and individual qualitative interviews and its analysis are also described.

3.4.2 Study Setting

The study took place at Hospice Africa Uganda (HAU). The site is located in Kampala with approximate population of 1,420,000 (UBOS, 2009). The choice of this site was based on response and expressed need or concern at Hospice Africa Uganda that my research questions aimed to address. Hospice Africa Uganda is the main institution offering palliative care to terminally ill people in Uganda. The institution offers palliative care training for Uganda and sub-Saharan Africa.

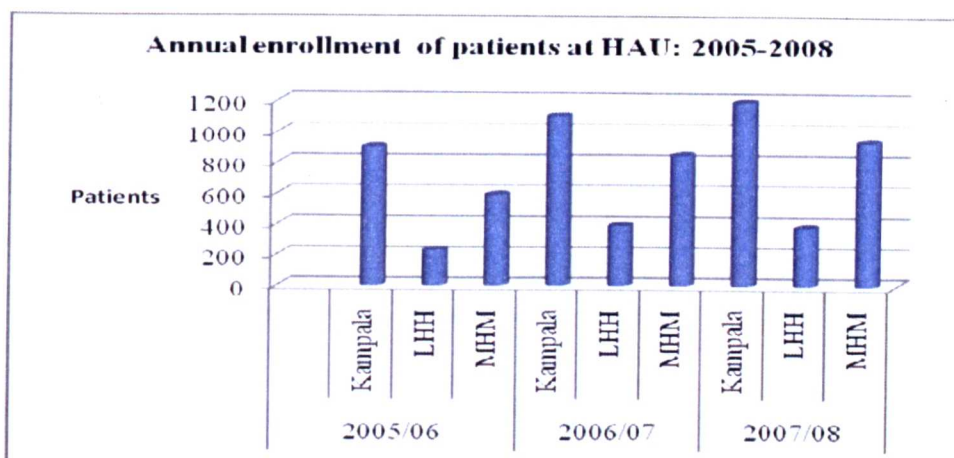
The majority of new patients with HIV/AIDS enrolling for palliative care at HAU have Kaposi's sarcoma and other cancers related to AIDS, for example, cancer of the cervix (patients with advanced AIDS). The majority of patients who utilize palliative care services are in their advanced stages of AIDS (*stage III & IV*). Multiple distressing symptoms associated with clinical stage III and IV and severe pain due to opportunistic infections and malignancies prompt patients to seek for palliative care.

Pain and symptom management commonly observed with patients with advanced AIDS is usually the beginning of journey to HAU. HAU provides day care support for patients in Kampala. Patients have opportunity to meet, support each other and have access to multidisciplinary team, which include social worker, psychologist, nurses, and doctors. This gave me an opportunity to study the new patients and their family members in the first phase as well as multidisciplinary team members in the phase two.

3.4.3 Sampling Technique and Recruitment of patients

Figure 3.2 shows enrolment of patients at Hospice Africa over a three year period (2005-2008). Based on the annual reports from the Hospice, the number of patients who sought palliative care at HAU in 2007/2008 was approximately 1190. This translates into about 100 patients per month. Of these, it is reported that approximately 32% of patients have HIV/AIDS and/ or AIDS related cancers (HAU, 2008), i.e 32 patients.

Figure 3.2 Number of patients enrolled at Hospice Africa (HIV/AIDS, Cancer patients and or both).



Key

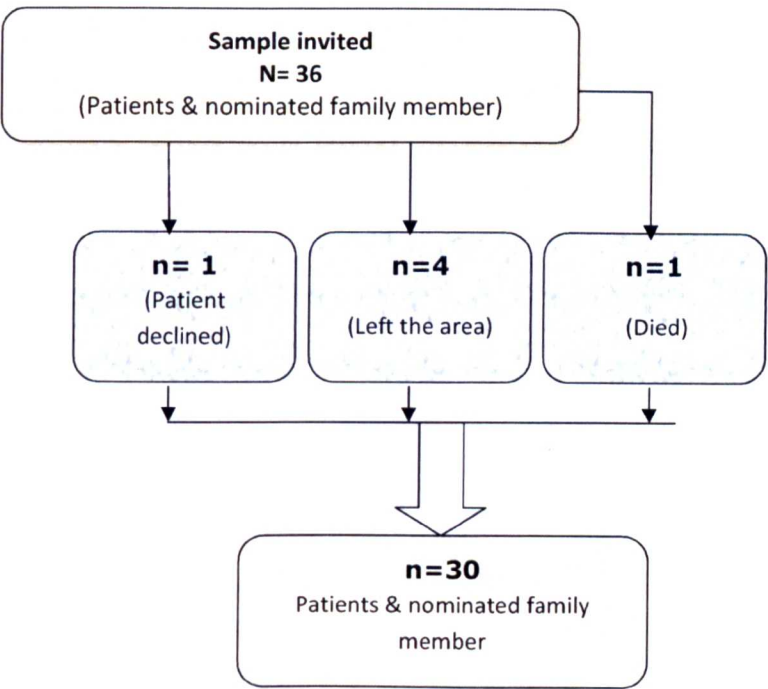
- *Kampala*- Study site used
- *LHH*- Little Hoima Hospice
- *MHM*-Mobile Hospice Mbarara
- HAU has three branches, study took place at the main branch: Kampala, Uganda

I carried out the study between January and mid June 2009. I recruited participants who were newly referred and seeking palliative care at HAU. I sought to recruit PLWA newly referred to HAU over a period of one and a half months, to allow time for follow up. Whilst the projected number of enrolment of patients with HIV/AIDS for one and half months was approximately 45, only 36 patients (with AIDS) were actually enrolled at HAU. All the 36 patients met the inclusion criteria (*see appendix IV*) and were eligible for the study. Thus, a consecutive sample of 36 participants was invited for the study. However one person declined, one died and four could not participate because of logistical reasons⁹. At least one nominated family member was recruited alongside each patient. In total, 30 patients and 30 relatives were recruited for this study. The patients recruited were followed up for a period of 8 weeks.

⁹ Left the area as soon as they were recruited, lost contacts or remained untraceable.

The following figure shows the recruitment flow chart for the patients and care givers.

Figure 3.3: Recruitment flowchart for patients and their care givers



All those patients over the age of 18 with advanced AIDS enrolling for palliative care services at HAU were eligible to participate in the study. To define the sample of patients with advanced AIDS, WHO proposed guidelines (*Appendix IV*) were used. To be eligible, participants were had to meet criteria for inclusion (*Appendix V*). Any two combinations of symptoms made on basis of clinical signs of advanced AIDS stage III and IV were taken to form sample for research study. The participants in phase one comprised of patients with advanced AIDS who were registered at the HAU care centre and who consented to participate. In addition, participants had to be free of any cognitive impairment and have the ability to communicate and to consent to study participation.

Recruitment commenced after permission was granted from HAU (*Appendix VII*) and Uganda National Commission for Science and Technology (UNCST) (*Appendix I*).

3.4.4 Accessing patients with advanced AIDS and caregivers

An information poster was displayed in the waiting area of HAU centre. The purpose was to inform the patients and caregivers of the study. The poster served as an opportunity to invite participants. Patients with their family members were invited to participate in the study. While recruiting patients, the study was described as an exploration of patient's experience of palliative care from HAU.

It was anticipated that patients with advanced AIDS would present at HAU for palliative care and symptom management. For the purpose of this study only those patients presenting for the first time were given opportunity to participate in the study. It was expected that at this stage (advanced AIDS) patients would be critically ill and there would be less likelihood that they would return back to HAU for further palliative care management, therefore appointment was made to follow up their care at home or place of choice at agreed appropriate time. All the participants who met the inclusion criteria (*appendix IV*) were given information on the study and invited to participate. On the first encounter, baseline information was collected from the participant and family care giver. Dates for home-visit were agreed and that they would be contacted before visit to arrange suitable time and location for interview. Information package materials that describe briefly the aim of the study and inviting them to participate were provided. A contact number was displayed in the information

sheets should the patients/family care giver(s) want to take it. It was anticipated that participants may be critically ill or potentially bedridden, therefore, supportive measures was planned to meet their individual needs and make them comfortable for the interview. Patients, however, were free to withdraw from the study should they feel quite unwell and not ready to participate or if they want to participate later, times will be re-arranged.

To access the family members/caregivers, an information sheet pertaining to the study was provided accompanied with letter inviting family members/caregivers to discuss their experiences regarding palliative care for their patients. Their participation was voluntary and their views were treated anonymously and kept confidential. Family members/caregivers who wished to be interviewed and discuss their views/experiences were offered consent forms (*appendix III*) and suitable times/location for interviews agreed. Family members were requested to have common dates of home-visit with their patient (s) as this was helpful and to safe time.

Convenience sampling was used as it is appropriate to enable extensive range of supportive caregivers available are given chance to participate in the research.

In order to understand how sampled patients were accessed out of HAU, it is vital to get insight into the model of palliative care delivery at HAU. The details of how model is operated is described in part 1.6.2.3 (of chapter one). Further to that, I have described briefly how accessing patients were done. In relation to community health worker, they played a role in two ways. First, it is assumed that they played some role in referral of some patients recruited at HAU. Second, in some instance, community health worker co-managed patients recruited. In such cases, community volunteers co-worked with HIAU staff to identify and intervene to help distressing patients recruited.

Some of the interventions were physical and psychosocial dimensions in their homes. However, community volunteer workers did not participate in my study as they were involved in another study at HAU. There was limited involvement of community volunteer workers in my study which evaluated community volunteer worker program at HAU (Jack, 2009).

For instance, CVW helped researcher to locate and provide useful information in tracing recruited patients in peri-urban part of Kampala for follow-up patients who, otherwise, would be difficult to access.

Given that participants recruited for the study were first met on their first day at HAU, it was assumed that they were referred (by either medical staff in various hospitals/community volunteer workers or self-referred). However, after enrolment into HAU, patients received care through several pathways spelt by Hospice Africa Model.

3.4.5 Data Collection

3.4.5.1. APCA African POS Tool

APCA-POS tool is used to measure the effectiveness of provision of palliative care to PLWA. The tool was developed in response to the absence of a rigorously validated outcome instrument that measures the quality of palliative care provision in Africa (Harding and Higginson, 2005). The tool was first developed in UK and has been rigorously tested for monitoring and evaluation audit to facilitate continuous quality improvement in palliative care services (Powell *et al.*, 2007). The purpose of this

measuring tool is to inform the ongoing process of improving quality of palliative care provision. In my research, the tool was used to provide insight and highlight the areas that need improvement to be taken up in phase two of the study. The tool: APCA African POS (*see appendix II*) uses patient-level indicators to evaluate routine clinical practice and experience care delivery (Harding & Higginson, 2007).

The above tool used in this study was validated in Africa (Harding *et al.*, 2010). Development of this study stemmed from lack or almost no evidence of palliative care tool in Africa (Harding *et al.*, 2010; Harding & Higginson, 2005; Hearn & Higginson, 1997). APCA African POS is a palliative outcome scale tool developed and validated in Africa (through African Palliative Care Association). Validation was conducted across 5 African countries services. After validation, APCA African POS has been found to be appropriate and relevant for both HIV and cancer patients in addressing family and patient's outcomes at all stages of disease trajectory (Harding *et al.*, 2010).

Given that palliative care aims to meet physical, psychosocial, psychological, social and spiritual needs of an individual at the end-of-life, holistic nature of palliative care requires that services be provided by a range of staff working in a multi-disciplinary team. Palliative care services must therefore reflect the issues which surround patient care, the services provided to the family as well as the complex relationship with service providers. To measure outcomes of in palliative care needed validated and reliable audit tool. Given that tool is sensitive to changes over time, it quite important and vital tool since it is responsive to changes in patient's condition. Hearn & Higginson (1999) in their review concluded that there is no single measure which addressed all key components of palliative care, hence therefore led to the development of the tool which was to overcome some of the limitations associated

with existing outcome measurements scales in palliative care (Hearn &Higginson, 1997). The tool offers opportunity for all symptoms affecting the patient to be raised.

Notably tool covers:

- Physical symptoms
- Psychological symptoms
- Practical concerns
- Emotional concerns-personal and familial
- Psychosocial needs-personal and familial

To address how patients with advanced AIDS (*stage III and IV*) with palliative care needs and their families experience care delivery and receipt, both APCA-POS tool and interviews were used. APCA African POS was used to evaluate the patient's level of indicator of outcome of care whilst use of in-depth interviews explored their experiences and care. To establish the experiences and care over a period of 8 weeks, a five-point sequence follow up of patient was established: first on the encounter, then weekly for 4 weeks and finally after 8 weeks.

The interpretation of the findings has been described in the following paragraph with the sample of APCA African POS enclosed in the figure 3.5 .

Interpretation the data on APCA African POS, the following table needs to be cross-referenced simultaneously in order to understand the values and what they mean. In chapter 6, I have presented some other parts as mean average of score which needs to be read in the light of what they mean. For instance, if an average of a given score, say symptoms experience in the first is given as 2.83, then I would round it off to one figure to get 3.00 to mean the symptoms were severe (as shown in the table).

Figure 3.4 APCA African POS tool used in the study

Q1 Please rate your **pain** (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days ☐ 0 Not at all, no effect

☐ 1 Slightly-but not bothered to be rid of it , ☐ 2 Moderately-pain limits some activity, ☐ 3 Less severely- pain limits most activity,

☐ 4 Severely-activities or concentration markedly affected, ☐ 5 Overwhelmingly-unable to think of anything else

Q2 Have any other **symptoms** (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days? Slight ☐ 0 No, not all, ☐ 1 Slightly, ☐ 2

Moderately, ☐ 3 Severely, ☐ 4 Unbearable, ☐ 5 Overwhelmingly

Q3. Have you been feeling **worried** about your illness in the past 3 days? ☐ 0 No, not at all, ☐ 1 Occasionally, ☐ 2 Sometimes-it seems, to affect their (your) concentration, ☐ 3 Most of the time, ☐ 4 Yes, always preoccupied with worry about me, ☐ 5 Overwhelming worry

Q4. Over the past 3 days, have you been able to **share** how you are feeling with your family or friends? ☐ 0 None at all, ☐ 1 Very little given, ☐ 2 Information given on request but would have liked more, ☐ 3 Information given but hard to understand, ☐ 4 Information given and understood, ☐ 5 Full information-always free to ask what I want, and talked freely

Q5. Over the past 3 days have you felt that **life was worthwhile**? [felt good about yourself] ☐ 0 No, not at all, ☐ 1 a little , ☐ 2 Occasionally , ☐ 3 Sometimes, ☐ 4 Most of the time, ☐ 5 Yes, all the time

Q6. Over the past 3 days, have you felt **at peace**? (not depressed) ☐ 0 No, not all, ☐ 1 Occasionally, ☐ 2 Sometimes, ☐ 3 Most of the time, ☐ 4 Yes, definitely/ all the time

Q7. Have you had **enough help and advice** for your family to plan for the future? ☐ 0 not at all, ☐ 1 Yes, occasionally, ☐ 2 Sometimes, ☐ 3 Yes, adequate, ☐ 4 As much as I wanted

Q8. How much **information** have you and your family been given? ☐ 0 not at all, ☐ 1 Yes, occasionally, ☐ 2 Sometimes, ☐ 3 Yes, but not much as I wanted, ☐ 4 Adequate, ☐ 5 As much as I wanted

Q9. How **confident** does the family feel caring for ____? ☐ 0 Not at all, ☐ 1 less confident, ☐ 2 Sometimes in doubt/unsure , ☐ 3 Confident with occasional doubt, ☐ 4 Confident , ☐ 5 Very confident

Q10. Has the **family been feeling worried** about the Client over the last 3 days? ☐ 0 No, not at all, ☐ 1 Occasionally, ☐ 2 Sometimes-it seems to affect their concentration, ☐ 3 Most of the time, ☐ 4 Yes, always preoccupied with worry, ☐ 5 Severe Worry

3.4.5.2 Qualitative Interviews

Whilst the APCA-POS questionnaire provided evaluative data about the impact of palliative care among advanced AIDS patients, in-depth interviews was also carried out among patients with advanced AIDS and their family members to establish experiences of living with HIV/AIDS as well as their experiences of palliative care. Interviews were carried out among the patients who met inclusion criteria (*appendix I*) and family members who were involved in caring.

All patients with advanced AIDS who are enrolling for palliative care at HAU were given opportunity to be interviewed for the study. Semi-structured interviews were designed to allow for focused and two-way communication. It was expected that by using in-depth interviews, participants would have an opportunity to express their thoughts and ideas regarding the experiences of care received and how enrolment with HAU has shaped their care. It was expected that participants would express themselves freely and maintain researcher-participant relationship which allows for open dialogue (Barker, 1996). Service user (patients with advanced AIDS and their families) interviews are aimed to elucidate and illuminate on the experiences of care given over a given period of time. Ideas and notes taken on the preliminary meetings provided clue and leads in the subsequent meetings/interviews. It is therefore through those subsequent meetings that shaped discussions. I made notes at each interview for tracking and reflective purposes.

To recruit family members for the study, patient participation confirmation sheet (*appendix III*) was offered and explained to the individual who was caring for the patient at home. Participants ticked the part allowing the person/individual from the family to participate in the interview.

Whilst interviews are most commonly used to gather information especially when events being investigated have already occurred (Grbich, 2007 & 1999, Green and Thorogood, 2005) it is a conversation that is directed, more, or less, towards the researcher's particular needs for data. Interviews seek to gain information on the perspectives, understanding the meanings constructed by people regarding the events and experiences of the participant's lives (Silverman 2010; Grbich 2007; Denzin & Lincoln 2005).

Three types of interviews namely: structured interview, unstructured/informal interview and semi-structured interviews. Structured interviews produces data which is quite tight and must follow specified set of questions, in specific order, this are usually used in survey designs. Unstructured/informal interviews are more like natural conversations that happen in the field. The common type of interview is in between the two and is called semi-structured interview. In semi-structured interviews, the researcher sets the agenda in terms of the topics covered, but the interviewee's response determine the kind of information produced about those topics and the relative importance of each of them (Silverman , 2010; Green & Thorogood, 2005).

I planned the time for each individual to help in providing supportive data in order to help to interpret the patient's story. Information about the participants included their experiences of palliative care services received, and progress of their illness, perception of care given, the times one has been receiving palliative care, description of how the palliative care services are received by patients at the community.

3.4.5.3 The process of interviewing

The process of interviewing took 3 phases: rapport-building, maintaining/middle phase and the conclusion. The following is the description of these phases.

i) Rapport-building phase

Interview process consisted of rapport building in the initial contact. Introduction was made during the first contacts with participants and researcher sought to maintain this relationship throughout the study. I played a significant role in active listening in order to explore various areas of attention. I used opening question: *can you tell me about your experiences living with HIV/AIDS?* This opening question provided an opportunity for participants to shed light on the past and current experiences of living with AIDS and what prompted them to seek help at the palliative care facility. Use and significance of tape recording was explained in this phase. Digital voice recorder was switched on in this phase.

ii) Maintaining/middle phase

During this phase the interview process was maintained. I developed and sustained trusting relationship with participants. Talking and sharing experiences freely enhanced and enriched contribution from participants. Mason (2002) emphasises the interactional exchange of dialogue by having conversations with purpose. This phase generated a lot of information for this research: experiences of palliative care given to patients with advanced AIDS.

iii) Concluding phase

At this stage of interview, the researcher asked the interviewee whether there was anything else he/she would have liked to share more with me. With this ending style, I

prepared interviewee to come to a smooth end of our interviews. This stage was challenging given that some participants still wanted to share their experiences. I took lead and appreciated the respondent for participation as well as answering any question that was posed by the participants.

The following figure shows the interview questions used in the study for phase one.

Figure 3.5 Interview questions in phase one: patients and care givers.

I: Patient

- Can you tell me more about yourself...
- Would you tell me the story, in any way you choose, of what happened when you first noticed you had HIV
- What made you to seek help in this facility... please tell me more... *about an event or important issue raised*
- What are your main problems of recent? Please tell me more... *so what happened after that....or please tell me more about an event or important issue*
- How has symptoms affected your *day-to-day life*? Please tell me more.. *so what happened after that... (to continue talking).*
- *How do you handle /cope with your illness?* Please tell me more..(*about an event or important issue raised*)
- What are your expectations of care? Please tell me more..

II: Questions to caregivers/nominated family member caring for the recruited respondent

- How do you care for the patient? Please tell me more... *(about an event or important issue raised)*
- What are the challenges/difficulties encountered while caring for the patient at this time? Please tell me more...(about an event or important issue raised)
- What your expectations of your responsibilities/roles in caring for the patient?... Please tell me more
- In your views, how best can you be assisted in your care delivery? Please tell me more ...(.about an event or important issue raised)

Clarification questions

What do you mean by that... would you like to tell more about that...please given an example...
Is there anything else that you would like to discuss with me?

The above questions were developed following critical review of literature into palliative care in Uganda over the last one year before data collection. My experience as a Registered Nurse with public health training (epidemiology) at Master's level and my practice and work with HIV/AIDS patients in Uganda as well as meetings with experts in the field of palliative care in Uganda, continued to shape the development of the above questions.

3.4.5.4 Interviewing participants: experiences of the process

I conducted in-depth interviews (single/joint) with patients and their caregivers in the fourth-round encounter (4th week). All participants were patients with advanced AIDS above 18 years. They varied in their gender, educational background, socioeconomic status, and level of engagement with care, family and living condition. Further, patients varied in location (rural, semi-rural or urban), care setting (home care, in-patient, out-patient and day care), the stage of patient's illness (*stage III or IV according to WHO classification*), on HAART or not and whether they had pain or not. Hospice staff (health professionals) assisted in recruitment in the sense that they identified the potential participants and referred to the study. Nurses and clinical officers working in palliative care team at Hospice Africa established a trusting relationship with the research participants. With the help of family member and community volunteers we were able to establish their homes and good rapport/working relationship with the patient (s) and family. When time came for conducting interviews, families already knew what we were doing and received us cordially. All participants were followed up for a period of 8 weeks except the 8

participants who died in the course of follow up. Interviews were then organized and conducted during their 4th visit in convenient location of participant's choice. Out of 30 research participants recruited, a total of 19 interviews were conducted in their homes during home-visits. Three participants were interviewed at the hospital. 8 participants were lost during the study as they succumbed to complications of advanced AIDS and died. APCA African POS was administered to all participants on weekly basis. Marginal allowance of tool administration was given as 3 days before or after 7 days/week cycle as recommended (Higginson *et al*, 2005; Higginson & Hearn 1999; Stevens *et al.*, 2005). This period allowed was meant to accommodate unforeseen circumstances when APCA African POS interview was missed on scheduled time: either patient was too ill to be interviewed or missed appointment or due to unavoidable circumstances there was no interview. Data collection in the 4th week was unique in the sense that POS was administered followed by session of interviews. It was generally perceived that tool does not take much of the patient's time, on average it took approximately 10-15 minutes in other studies (Stevens 2005; Higginson & Hearn 1999).

Qualitative interviews were conducted with the aid of interview guide. Patients generally spoke freely and with ease during the interviews except in some few cases when presence of a family member created uneasiness. This was observed particularly among the 4 patients who had not fully disclosed to their family members. I was keen to observe the trend of discussion and when it was difficult to share sensitive issues, I used silence or break to ease and allow participant to ventilate feelings. I would seek for patient's view about the question posed whether he/she was willing to share or not. I would observe some short silence when patient broke into tears while sharing her experience and revisiting the issue of consent to continue or not. These experiences

were emotional to me also: I could be shocked during some interview times. I was careful with patients who were too ill not to distress to them with interviews. After written informed consent, participants shared their information regarding living with HIV/AIDS, support and care they have received, life situations growing up with their illness and how they have responded. Questions also focused on the experiences after enrolling at Hospice Africa and such areas as networking with other HIV/AIDS agencies providing HAART, radiotherapy and chemotherapy. Caregivers were also given opportunity to share the experience of taking care of their patient with advanced AIDS. The issues that arose in this phase were further explored in the second phase during the encounter with the hospice staff (health professionals). The implication of current practice, experiences and issues relating with policies were further explored with key experts of palliative care in Uganda. Field notes were carefully written for each patient to complement information digitally-recorded from interviews conducted once for each patient with their caregivers. These data was analyzed qualitatively and described thematically in chapter four and five.

3. 4.5.5 Joint and individual interviewing in the context of HIV/AIDS

Interviews were conducted at home (except 3 patients who were hospitalized). The interviews lasted for a period of 25 minutes to 45 minutes and were digitally recorded to be transcribed. On arrival I would explain the research study and answer any query the patient and family have thereafter informed consent was given to them. Patient was requested to nominate carer of his/her own choice. It is during this time that the patient's preference for joint interviews/single interviews was established. The dyads who affirmed that they preferred joint interviews (n=16) while those who did not like to be with caregivers (n=4); while the remaining patients did not have carer at all

(n=2). Interviews began with the opening questions which sought to have participants narrate their account of living with HIV/AIDS while reflecting on coping strategies. Patient could be requested to tell a story from the time of one got the disease to date. Follow up questions were posed to enable patient reflect on what was helpful or not in their experience of living with HIV/AIDS as well as exploration of support network established since contracting HIV/AIDS. Further the interview established the experiences after palliative care interventions were started and what the patients would like to tell other patients in similar condition.

Joint interviewing has been rarely explored as one of the qualitative method, instead individual interviews have become the custom (Barbour & Kitzinger, 1999). There is little documentation regarding interviewing two individual concurrently (Song, 1998). Seymour, Dix & Eardley (1995) proposed that in day to day living, realistic and social salient features of some interviews often imply that interviewers find there is a second individual during the interviews contributing even if the interviewer planned to have individual interviews. This is true especially in interviewing patients with HIV/AIDS and their caregivers in African context where it is difficult to keep out an individual in his or her own home. Most African communities view patient's needs/experiences as communal requiring presence of another individual to signpost the relationship and responsibility of caring. With the advent of joint interviews in my study, methodological and ethical issues arose, and had to navigate and accommodate special cases with flexibility in adopting joint interviews. While I had earlier planned to have individual interviews, asking patients with advanced AIDS to recount their experiences of living with HIV/AIDS and getting care necessitated presence of other individual who in most cases happened to be main care giver and supporting the

patient. Some patients felt that there was no secrecy to necessitate individual interviews. This was particularly common with couple interviews-when one partner was suffering from HIV/AIDS and the other was the main care giver. In cultural context, separating an individual for an interview often could be perceived as increasing patient's burden (Morris, 2001), therefore many caregivers/family member or individual (s) was in most cases present to help their patient complete interviews and support patient in giving recount of experiences (represent) especially if their patient was bed ridden and was doing too poorly. While some caregivers or family members felt that they were giving right account of their patient during joint interviews, it was not a true to all; patient's account of their experience could have been misrepresented by caregivers.

Morris (2001) documented experiences whereby main carer's own needs are likely to overlap and appear similar with or different from those of the patient. This could raise the ethical dilemma on issues relating to intrusion, inclusion and confidentiality which was problematic to handle. Radley (1998) has suggested that in doing joint interviews, it can lead to antagonism especially when it comes to level of disclosure which was common phenomenon with some patients living with HIV/AIDS. In a case where caregiver has not been disclosed, patient was uncomfortable and causing distress to share his/her living experiences in presence of another individual. In such common cases during my study, patient's choice was respected and encouraged to give the account of his/her experience in a suitable and private convenient location. While giving the opportunity for patients to decide on joint/separate interviews as an approach of showing respect and offering degree of empowerment, unfortunately, patients who opted to have separate interview, themes of exclusion and not feeling part of the society were echoed. Arksey (1996) admitted that joint interviews presents

with such challenge as having one person dominating the discussion. In my study, specific requests were made to allow an individual to expand on a particular situation or comment, a step that moderately controlled the effect of domineering. In joint interviews it was clearly evident that family carer was spokesperson of the patient which displayed changing dynamics in the family and in most cases it shed light on their own parameters of active participation to offer care for patient.

The experience of collecting data in joint interviews has also presented to me an opportunity to realize how imperative this approach not only in providing rich data but also in creating platform to discover different areas to be explored/studied. Among the areas that joint interviews presented to me was chance to observe the interaction of caregivers and patients (in their joint construct/validation process) as well as their experience of confronting reality of living with HIV/AIDS and how they each of the dyad shared or differed in understanding and perceptions about lived experiences. Seymour (1995) has encouraged use of such approaches that spawn rich data and also adequately address objectives of the study which to me, joint interviews was more acceptable in African culture and produced a lot of data for this study. I found joint interviews particularly unique in the sense that majority of patients living with advanced AIDS were bedridden at homes and in their villages living in small or limited space and in most cases sharing the same room with the carer, a space-bound observation which limited one's living condition and could make it difficult to ask someone to leave his/her own house. In some instance, patient sat on the public corridor outside the room because it was not enough for us to enter room, an interview- venue crisis that could only be resolved through striking agreeable and suitable site with assistance of the caregiver.

Whilst joint interview presented to me ethical dilemma in the sense that the pair could be observed echoing each other's words in areas that seem important to them, sensitive issues raised during the research might not have been adequately addressed as questions surrounding full disclosure and shared information still exists among patients living with HIV/AIDS. Cornwell (1984) suggested that shared words can be taken to demonstrate public rehearsed accounts with the implication that their contribution is somehow less true than private accounts. This is because dyads joint interview is characterized by pre-existing relationship which makes it more likely to have some common shared understanding of events/experiences unlike focus group discussions.

It was generally observed in the study that during the process of conducting joint interviews, participants would be heard agreeing on certain explanations and therefore participate in the joint validation course through influencing or reinforcing what the other can recall. This observation however would also present with challenge of control (who is influencing who) or when should someone speak for someone else or influencing each other in validation process (Edwards & Middleton, 1986; Wilkinson & Kitzinger, 1996). Joint interviews also provide a perfect opportunity to explore different emphasis from the dyad culminating from the discussion. Where differences were observed, the researcher can take note of it and further explore.

In conclusion, the joint interviews approaches are still unexplored field in health research worth giving attention. This is reflected in the difficulty searching for the literature supporting utilization of this approach yet it is commonly used while collecting data through interviews. Joint interviews presents opportunity for dyad to express joint construction of an experience or helps in understanding the relationship

between patient and caregiver. The challenge that I found in this approach is the unspoken rules of engagement between stranger (researcher) and two different who have pre-existing relationship. My role was more of connecting the two in the discussion and guiding the discussion, an experience which I felt needs special skills. The approach require one to have full details (field notes) of the context of discussion in order to understand the meaning of conversation since the utterances are product of environment (interaction and broad context) (Morris, 2001).

3.4.5.6 Field-Notes

Alongside collecting information using interviews, the researcher looked at the manner and ways in which care is given by the family members. Field observation and note-taking helped generate data on wide range of social dimensions of social world including daily routines, and ways in which social phenomena occur or performed in the context of 'setting' which cannot be captured through questionnaire or interview (Mason, 2002). Field-observation took into account the 'setting' where care was given at different contexts (community/home/facility). This method particularly was significant in generating multidimensional knowledge that cannot be constructed in the interviews in context of delivery of care to patients with advanced AIDS at the community. Mason (2002) holds the view that observation allows the generation of multi-facet data on social interaction in specific context as it occurs rather than relying on people's retrospective accounts and on their ability to verbalize to reconstruct a version of interactions or setting. Since field-observation was ongoing alongside other methods of data collection, patients and family members were made aware of this

through invitation notices at the reception. Whilst Lincoln (1994) has outlined ethical problems involved with this method, every effort was made to maintain privacy as well as disclosing the research study and what it entails at every stage. At the end of the meeting with participants, I noted down the important features observed that had a bearing towards how palliative care is delivered.

3.4.5.7 Translation

One of the logistical challenges in the study was translation. The study was conducted in Uganda where there are over 42 tribes with different cultures. Majority of Ugandans spoke in Luganda while others spoke English with varied levels of proficiencies. With this in mind therefore, the study could be considered as cross-cultural research which introduced methodological challenges of adequacy and accuracy of translation in the light of cultural diversities such as that of Uganda. I noticed that language is definitely considered an important element which has overarching impact on research process as a whole. Recognizing this fact, I sought to describe solutions which I used in this chapter in order to take into account all the steps necessary to keep the translated information and reporting as neutral, objective and honest as possible. I must acknowledge that there was a challenge in cross-language interpretation. Cognisant of this fact, I sought to have trained bilingual person to play a double role as translator and also interpreter in order to maintain systematic and consistency in contents or qualitative data. I also set measures where I played an active role to keep quality control of interviews. Since some interviews were done in English, I tried to compare notes with those translated (done in Luganda) for quality control. In doing this, it gave me confidence that translated versions shared similar views which I built themes of this study. Further actions to monitor quality

control of interviews were made. For instance, I ensured objective measures on translation procedures were monitored for quality assurance. Translator was particularly useful in APCA African POS interviews in the event that subject/participant did not understand the tool in English.

In line with the fact that I saw myself as an objective instrument of research as well as my translator, elimination of possible bias was my main concern. Therefore, there was an agreement to ensure that translation of data from the source was back-translated by other independent person to keep quality assurance. I followed the following steps in translating the interviews into English. First, all the words in Luganda were translated to be free of any colloquialisms or ambiguous phrases then I had bilingual translator who competently translated Luganda into English. This was followed by quality assurances checks: I got another competent translator who blindly translated some versions of scripts (randomly selected) from English to Luganda and then I called another third person competent in Luganda and English with experiences of translating to rate and compare the scripts. Any inconsistencies were noted in back-translations and were evaluated to check whether the original meaning was maintained or lost. At that level, if there were any discrepancies in the words or phrases were further revised after further consultations. I ensured that final scripts translated (*which were finally analyzed*) had similar responses to original versions when back-translated or vice-versa. These steps were keenly followed so as to minimize any chance of introduction of interpreter bias. In line with other studies on translation barriers in conducting qualitative interviews, there seem to be no such standards for translation of cross-language qualitative research Lopez *et al.*, 2008; Lason, 1991; Temple & Young, 2004; Pitchforth & van Teijlingen, 2005; Twinn 1997). However, there is

generally accepted approach that translation should produce as accurate as possible to the text, express all aspects of meaning in a manner that is understandable (Lopez *et al.*, 2008; Temple & Young, 2004; Harrington & Turner, 2001).

The problem and challenge of adequacy in cultural representation especially in translating assessment tools or questionnaires to local language has been reported in other studies (Hunt & Bhopal, 2005; Jorm *et al.*, 2005; Mc Laughlin & Sall, 2001; Shklarov 2007).

In other instances, some interviews were done in Kiswahili, a language that I am fluent in speaking and writing. In such cases, I translated and transcribed it into English. It offered me an opportunity to discuss points in text where I had to stop and think about meaning. This experience has also been reported in other studies where translators regard the discussion of the translation processes as a check to the validity of interpretation (Temple & Young, 2004; Young & Ackerman, 2001). In playing translator role, I had an opportunity as researcher to draw close attention to the meanings and interpretations of experiences of living with HIV/AIDS which brought me closer to the research questions.

3.4.5.8 Follow-up

Participants for phase I was followed up for 8 weeks. The newly registered members at HAU were given opportunity to participate in the study. Participants recruited were informed of the study at the reception unit at HAU. At the reception, there was information package of the research study as well as posters. I carried out verbal explanation of study to patients who were enrolled for their first time. Consent form (*appendix III*) was presented to those who are interested to participate in the study. Participants who met inclusion criteria (*appendix IV*) were assisted to fill the questionnaires at the HAU after initial assessment and registration by HAU staff. Fundamentally, the first encounter provided the baseline information concerning the experiences of living with HIV/AIDS. Primarily, the subsequent follow-up visits of patients enrolled at HAU provided useful information on the experiences of care and measurements of patient's level variables using APCA African POS tool.

3.4.6 Analysis of Data

Qualitative analysis of individual interviews is described in part 3.5.3.1. The following is the description of quantitative analysis of APCA African POS tool used in the study phase I.

3.4.6.1 Quantitative analysis: Data analysis and interpretation of POS data

This section describes analysis of APCA African POS data used to collect the data from patients and care givers in phase one. The following is the description of the analysis and interpretations.

The findings from this tool were analyzed using SPSS. Salient and significant leads and major findings in this phase informed phase two part of the study which targeted palliative health care workers. Analysis of APCA African POS data focused on the ongoing comparison of scores on a case-by-case basis. Scores were analysed to monitor patient's clinical change over time for each item while difference in scores between patients and staff highlighted issues that staff to would follow up with patients thereafter. To obtain complementary information, socio-demographic profile and information of participants were included in the APCA African POS in order that meaningful comparisons between groups can be done as well as obtaining characteristics of patients.

One of the statistical tests that were used was Wilcoxon Signed Rank Test. According to Pallant (2007) in a step-by-step guide to data analysis using SPSS version 15, Wilcoxon Signed Rank test also called the Wilcoxon matched pairs signed ranks test is one of the non-parametric statistical tests designed for use with repeated measures. This statistical analysis is used when subjects are measured on two occasions or under two different conditions. Wilcoxon Signed rank test compares the subjects at Time 1 and Time 2. In the case of this study, participants were followed up for five times (*Time 1, 2, 3, 4 & 5*). To apply this statistics, the data set in data base was coded in such a way that two groups could be analyzed at ago: 1st group (*Time 1 & 2*), 2nd group (*Time 2 & 3*), 3rd group (*Time 3 & 4*), 4th group (*Time 4 & 5*). Using this statistical test, I was able to track the changes between Time 1 & 2, Time 2 & 3, Time 3 & 4 and finally Time 4 & 5.

In order to interpret this, two things were considered. First, the **Z** values and the associated significance levels, presented as **Asymp. Sig. (2-tailed)**. If the significance level is equal to or less than **0.05**, one concludes that the difference between the two scores is statistically significant and we can conclude that two sets of scores are statistically different. Second, the effect size. The effect of size for this test can be calculated by dividing **z** value by the square root of **N**. Given that **N**= the number of observations over the two time points, not the number of cases. Therefore, the effect of size is given as **r** values which can **0.1** which means small effect, **0.3** means medium effect, **0.5** means large effect. Similar to my study sample size, Pallant (2007) used same sample size in page 225 to demonstrate application and usage of this type of analysis.

Another test which I used was the Friedman test which is also non-parametric alternative to the one-way repeated measures analysis of variance (in parametric statistics). It is also used when there is same sample/subjects or cases that are followed up and one wants to measure them at three or more points (five points in this study), in time. It specifically addresses such research questions: *Is there change in variable Z scores across five points? Followed up?* What is needed is same sample or subjects/cases followed up over sometime. It is significant that Pallant (2007) in example given in page 229 uses sample size of 30 to analyze using this test.

The results of the Friedman test is indicated as statistically significant if the test indicate a Sig. Level less than 0.005 (in comparing the groups across the time period). It also uses chi-square to establish these significance levels.

3.5 PHASE TWO STUDY

3.5.1 Study setting

The study at phase two took place within the HAU and its outreach facilities. It consisted of individual interviews and focus discussions of palliative health care staff. A convenient time and appropriate location were chosen by the participants.

3.5.2 Sampling and Recruitment of palliative care staff

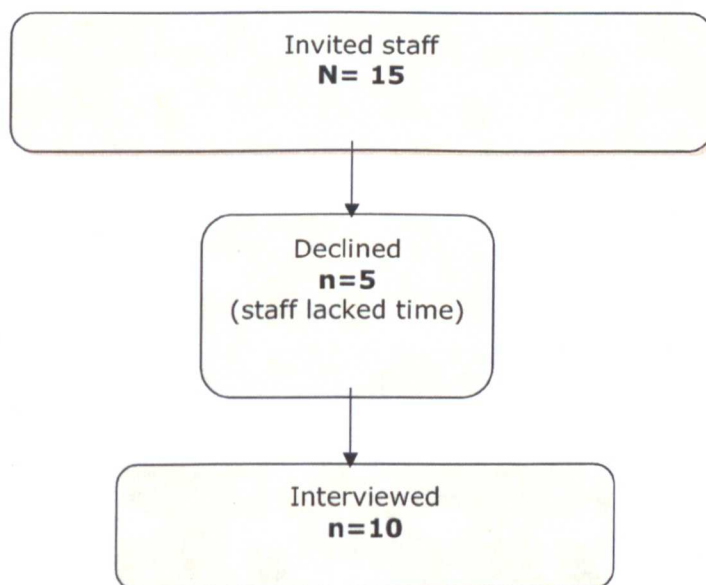
Approximately 80 palliative care staff were working in various parts of Uganda in 2009. The majority of these staff served in hospice settings and referral hospitals in various parts of the country. In Kampala, (Hospice Africa Uganda) 15 staff were identified as potential participants in the study (*see inclusion and exclusion criteria in appendix X*). The rest of the staff were either involved in paediatric palliative care or non-clinically involved. In addition, one doctor worked in a palliative care unit in a national referral hospital in Kampala which was outside study site.

Participants invited played a key role in delivery of palliative care service to PLWA at HAU. Figure 3.7 shows the recruitment flowchart for palliative care staff interviewed. Out of 15 participants invited, five declined, making the final sample achieved 10. These participants engaged directly with patients through various models of delivering care.

In phase two, the main research questions addressed were: how do health care workers seek to respond and address patients' and family caregivers' needs, what are the

barriers towards implementation of integrated palliative care and what is the way-forward increase palliative care coverage to PLWA. Phase two sought to gain an understanding of how palliative care staff deliver palliative care and challenges they encounter in the process. Fundamentally, the ultimate aim of the phase 2 was to establish challenges, opportunities and ways forward to improve and scale up the quality palliative care and end-of-life care amongst patients with advanced AIDS. Use of individual interviews and focus group discussions where possible for palliative health care workers were utilized during this phase. The following figure shows the recruitment flow chart for palliative care staff interviews.

Figure 3.6: Recruitment flowchart for palliative care staff interviews



The following table 3.1 shows the palliative staff interviewed and their responsibilities.

Table 3.1 Responsibilities of palliative care staff interviewed

Number	Responsibilities of palliative care staff interviewed.
1	Palliative care nurse
2	Pharmacist
3	Clinical Director, HAU
4	Quality Assurance nurse
5	Community volunteer worker’s coordinator
6	Clinical Registrar, HAU
7	Senior advisor, Policy, Medicine and Advocacy
8	Founder and Director International Programs
9	Social worker
10	Palliative care nurse

3.5.3 Individual interviews

The following figure shows the questions included during the interviews with palliative care staff.

Figure 3.7 Interview questions used in phase II: Palliative health care staff

- Can you tell me more about yourself? And your experience of offering palliative care services to PLWA at HAU
- What have been individual patient's main problems? Please tell me more...
- You mentioned earlier on that (event) is....(point of clarification) would you say more or elaborate, tell me more...
- How do you respond to these problems? Please tell me more....
- What are the main obstacles/challenges of palliative care service delivery to PLWA? Please tell me more...
- What are your views on possible way-forward in addressing these issues (raised in the interviews- I would probe systematically, according to issues raised).
- Probe took specific dimensions depending on the line of participant's experiences....
- Clarification questions
- Dimension of probe was in practice related challenges, service related challenges. The probes were along the line of practice, education, support, drug, policies, advocacies...of palliative care service for PLWA.
- What do you mean byplease tell me more about...

The above questions were developed as a result of critical reading and review of literature on palliative care in Uganda over the last one year before data collection. Following discussions with manager of HAU, she has agreed to have staff interviewed and also expressed interest to have other key managers interviewed as well. With this support, palliative health care staff were identified and given opportunity to participate

in giving their views on experience of palliative care delivered to patients with advanced AIDS.

To recruit participants in this phase, an open meeting was organized and an information sheet of invitation (*appendix VI*) was circulated amongst staff. This meeting gave an opportunity for palliative health care staff to ask questions as well as interact with researcher for any further information.

Once permission was granted, palliative health care staff were contacted to gain consent (*appendix VIII*). Interviews lasted an hour though this depended on how much respondents share. Descriptions of how individual interviews were analysed are shown in part 3.3.4.2. After individual interviews were conducted, a focus discussion was organized where palliative health care staff were invited.

3.5.4 Focus Group Discussion

A total of 15 active palliative care staff involved directly with palliative care service delivery to PWLA were invited to take part in a focus group at a preliminary meeting. Participants invited included individuals who had previously participated in individual interviews. While 15 staff were invited, 6 participants did not participate due to various reasons¹⁰. Thus, a group of 9 individuals participated in one focus discussion held at Hospice Africa Uganda. These particular staff were directly involved with palliative care services to PLWA who participated in phase one study.

¹⁰ Had participated in an individual interview before or lacked time due to workload at the time of focus discussion

The focus group was composed of different individuals with rich experience and was representative of the health care staff at HAU. As noted in table 3.8 which describes participants who participated in individual interviews, the focus group discussion included staff with varied experiences, roles and responsibilities. Thus, the team was perceived to have ability to yield in-depth information on shared problems, difficulties and challenges of delivering palliative care in responding to palliative care needs of PLWA.

In the literature, focus groups have been used to examine wide range of health issues (Kervern, 2001; Parsons, 2000) including recent medical research (Borgostron, 2010). Focus discussions have been used to explore solutions to a particular problem as a unit (Kitzinger 1995) as well as to complement other methods, especially in validity checking when the data is triangulated (Morgan 1997). In other instances, the gap between what staff or individuals say and what happens in reality can be better understood (Barbor, 2005; Kitzinger, 1995) because there are multiple understandings and meanings that are revealed by participants in focus discussions. In relation to health services, focus groups have been used to explore such issues as health professionals' response to changing needs of patients (Kervern, 2001). In addition, focus group discussion can be a powerful research tool which can deliver valuable spontaneous information in a short time and at a relative low cost (Morgan, 1997). This is because participants have opportunity to build on each other's comments as it stimulates thinking. Focus discussions can produce high quality and rich data because respondents have opportunity to clarify and respond to questions (Barbor, 2005; Kervern, 2001).

3.5.4.1 How focus discussions were conducted

I first planned for an open meeting with staff to explain my study. In this first forum, staff were given opportunity to ask questions and get clarifications. I then invited them to the study and expressed my interest in having their views and opinions on palliative care service delivery to PLWA. After the first meeting, I arranged for convenient time and location for focus discussions for eleven staff who accepted to participate in the study.

In all the process of conducting focus discussions, I maintained reflective thinking and critically evaluated my role and impact on the whole process. I ensured that I remained as objective as possible. I made sure that all the participants read the information sheet, and understood it before signing to participate in the study. Bryman (2004) and Silverman (2010) have highlighted need to explain procedures to participants before discussions.

I moderated the focus discussions throughout. I used probes for more detail and made sure that the discussion did not digress and tried to ensure that everyone participated and gave an input. Parsons and Greenwood (2000) have reported need to have moderation which ensures no one who dominated the discussions.

In the light of suggestions by Parsons and Greenwood (2000), I spent my initial time in helping the respondents/health care staff to relax. Then it was followed with session of explaining the study and why I involved them as palliative health care staff. I then negotiated starting time and anticipated time of focus discussions to avoid disruptions during focus discussions. I left it open to anyone who wanted to leave before the end of discussion, however, it should be noted that none of the participants left early. I

explained to participants who were health care staff about anonymity and confidentiality and also asked everyone to respect this by not passing on what has been said in the group to third parties. This was in consistent with ethical considerations (Bryman, 2004; Silverman, 2010).

I used list of questions as stated in the interview schedule and allowed the discussion to flow freely. As a moderator, I tried to get as many views and opinions as possible. Norman and Denzin (2009) have reported that focus groups can produce detailed information because there is opportunity to probe for clarification to seek to understand diversities and differences in views and opinions. I employed skills and techniques as suggested by qualitative researchers (Bryman, 2004; Morgan, 1997; Parsons & Greenwood, 2000; Silverman, 2010).

The focus discussion took about an hour and half and after that I concluded by thanking each participant. In the main part of focus discussion, there were often some awkward presenting situations and I learnt how to deal with them. Some of the strategies used included use of break-away conversation such as 'I am sorry, would you mind to explain further....or continue discussing with the group as this is interesting?... I also used silence as a strategy to encourage some individuals to speak and I would ask the question again if there were prolonged silence or use probes. I promised research participants that I would share the study findings when I finalize write-up. I also learnt that some crucial issues emerged immediately after focus discussions as some clarified some points and expressed themselves well. I jotted down their views as notes and I would return to them during the analysis. I also left my contacts details in case any of the participants wanted to follow up any issue raised during the discussion.

The following are the questions or guiding questions used during the focus groups.

Figure 3.8 Questions used in the focus group in phase II

- What has been like offering palliative care services to PLWA? Would you tell me more.... (I moderated team to ensure balanced contribution)
- Please tell me more about models of palliative care delivery to PLWA.. clarify..
- What have been the main challenges that you are faced so far? Please tell me more.... (would you please clarify..../ what do you mean by/ would you please talk more about that..../anybody else who would like to add/contribute...)
- How is palliative care services offered to PLWA? At HAU? How about 20km perimeter? How do you respond to PLWA who live outside catchment areas? Network with hospitals around Kampala and communities?
- How about way forward, respond to these challenges? How do you see yourself in the next 5 years to come? How do you plan to attain that? Opportunities available?
- Is there anything else you would like to share

3.6 PHASE THREE STUDY

3.6.1 Introduction

This phase describes study setting, sampling and recruitment process of key stakeholders in palliative care. These participants are key experts and influential in policy developments and have influence on palliative care service delivery in Uganda. This part further describes how data was analyzed. I begin with description of study setting.

3.6.2 Study setting

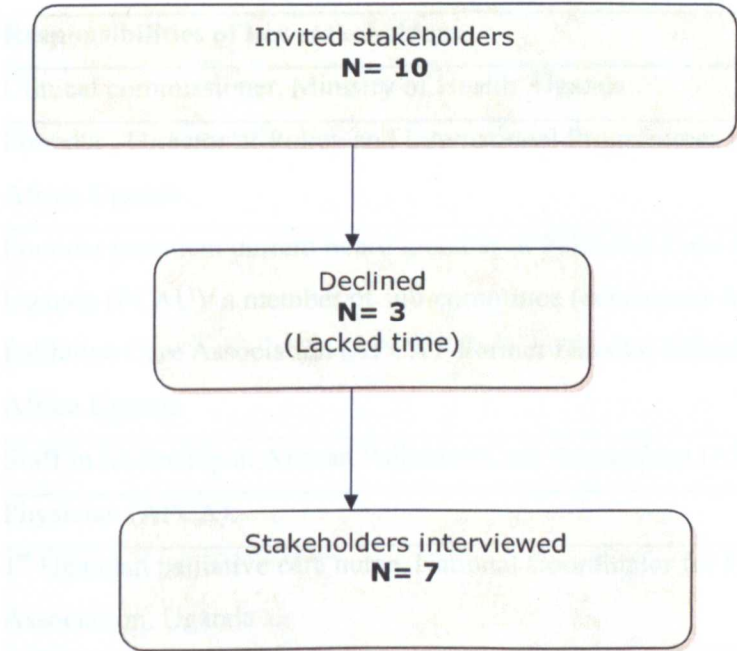
The study phase III took place within Kampala, capital city of Uganda. The setting envisaged instrumental participants in key institutions, organizations, ministry of health who are palliative care stakeholders. Location was strategic for sampling and recruitment of study participants for phase III whose participations based in the capital city of Uganda-Kampala.

3.6.3 Sampling and Recruitment process

I recruited participants from wider institutions including governmental and non-governmental organizations. Table 3.9 describes the characteristics of the participants used. Participants targeted were thought to have influence and capacity to shape palliative care service delivery in Uganda. These participants were either senior government officials (Ministry of Health), leaders of palliative care institutions and organizations in Uganda, policy and advocacy officers in Uganda or palliative care research experts.

A purposive sample of seven stakeholders of palliative care service delivery was selected to participate in this study. The following figure describes the flow chart for the key stakeholders interviewed

Figure 3.9 Recruitment flow chart for key stakeholders interviewed



It was hoped that participants from these institutions were the most appropriate given their capacities and involvement in palliative care service delivery. Some of their responsibilities have enlisted in the following table 3.2.

Table 3.2: Responsibilities of the key stakeholders interviewed

Number	Responsibilities of key stakeholders
1	Clinical commissioner, Ministry of Health, Uganda
2	Founder , Director of Policy and International Programmes for Hospice Africa Uganda
3	Founder president/current board member of Palliative Care Association of Uganda (PCAU)/ a member of sub-committee (education)-African Palliative Care Association (APCA)/ Former Director Education, Hospice Africa Uganda
4	Staff in leadership at African Palliative Care Association (APCA)
5	Physician (APCA).
6	1 st Ugandan palliative care nurse, National Coordinator for Palliative Care Association, Uganda
7	Palliative care expert with special interests in HIV and palliative care in sub-Saharan Africa

To access these individuals, I made arrangement to visit them. In the first visit, I was given opportunity to explain overall aim and purpose of the study. Study materials were given to potential participants. There was an opportunity for potential participants to ask any question and get clarification. During the visit, I asked whether the respondent was willing to participate in the research. Further appointments were scheduled for all respondents who consented. Ethical considerations were observed in all steps to recruit participants.

At the actual interview day, all respondents read the information sheet and signed consent form to participate. I also explained briefly how I would carry out the interviews and use of voice-recorder. All the interviews took place in a convenient location that suited respondents. Respondents were all made aware that they would be free to participate or withdraw from the study at any time.

All participants in this phase were individually interviewed. Preliminary questions were simple and easy to keep respondents relaxed and at ease and also get participants talking (see figure 3.10). I would then follow up with more specific questions in the main part which addressed palliative care service delivery to PLWA. Such questions as: what are your views and opinions on challenges related to palliative care service delivery? What would be the way forward... how can we better the palliative care service delivery?... please tell me more....., I would pick up the discussion in respective to how interviewee responds.

The following figure 3.10 shows the interview questions used in phase III study

Figure 3.10 Interview questions used in phase III study

- Can you tell me about yourself?
- Can you tell me more about palliative care services in Uganda?
- Would you like to tell more about (an event) that you just talked about now ...
- Would you explain to me further...?
- Can you me more about obstacles, challenges of offering palliative care services to especially at local and national level..?
- Would you like to tell more about (an event) that you just talked about now ...
- Would you explain to me further...?
- Would you share more light on palliative care services/scope of services for PLWA.. How about hindrances? How have you managed to address those challenges?
- Probe more on practice- palliative care implementation-training, support, policies, advocacies....
- How about palliative care policies and advocacies...? Past, present and future plans
- Do you feel that there is more that needs to be done in area of palliative care for PLWA in Uganda?
- (if yes), would you explain to me please....
- What are the opportunities to improve on palliative care services to PLWA...
- Way forward? ...
- Clarification questions
- What happened next? What were the implications? How did you work out that...?
- Is there anything else that you would like to share with me?

In the conclusion, I gave participants an opportunity to ask any questions that would be in their mind. I also took an opportunity to thank participants for their participations and informed them of what was going to happen next: data analysis, writing up the findings and sharing the results with them. I also mentioned the possibility of disseminating findings in conferences and publications.

Interview findings were analyzed in similar way as interviews of health care workers in phase two. I also employed other strategies to reduce/ minimize bias in decisions about what to present. One of the strategies used was the involvement of supervisors in discussing the themes. I aimed at presenting all sufficient data to support the findings of the study and also aimed to present any contradictory data if there was any.

3.6.3 Qualitative data analysis

This part describes the qualitative data analysis of interviews and focus group discussion. The first section describes analysis of interviews undertaken amongst patients and caregivers and also with palliative care staff. The second section describes analysis of interviews undertaken with key stakeholders and focus group discussion.

3.6.3.1 Individual interviews: Qualitative analysis

Qualitative research can produce vast amount of data which needs to be analysed properly in a systematic and rigorous manner and this is therefore labour intensive and time consuming (Denzin & Lincoln, 2005; Mays and Pope, 2000). Transcripts and notes provide large amounts of textual data but the researcher has to make sense of the data by transforming the data, sifting and interpreting them in order to formulate explanations of experience (Grbich 2004; Boeije, 2010; Mays and Pope 2000).

In this study, after every interview with patients and relatives and with health care staff, digitally-recorded interviews were immediately transcribed and translated from Luganda (when Luganda was used in the interview) to English. Field notes recorded

to some extent a broad summary of key issues in the interview and so could be used to cross check the broad meaning of the transcript. Field notes also offered an opportunity to counter check for inconsistency or missing points as expressed in the interview due to some interruptions at the time of interview.

I prepared the transcribed data so that it was presented in such a manner that it could be read quite clearly line by line and then condensed to produce meaningful units. This process is vital because it enables easy breaking or dividing of data into small units (phrases, sentences or paragraphs) in order to assign a label to each unit.

I tried to understand and summarize the whole story (in chapter 4) and then looked within each story for material which could be extracted and compared across interviews, using an approach involving identification of units and themes(May, 1998). The analysis of all interviews resulted in consolidation of these units to form themes and sub-themes. I continued with this process until all transcripts were analysed and there was complete representation of data.

Some authors have suggested that qualitative analysis can be done manually instead of using computer software (Creswell and Plano Clark, 2003; 2011; Bryman, 2004). I did not use the computer software, instead I used the following approach: I assigned the code words to text segments or units in one margin (in left side) and then recorded broader themes in the other margin (right hand side) of the verbatim transcripts. This process was followed by careful sorting of data in order to organize similar data units to form a theme. Robinson and Trolley (2005) have supported this approach while suggesting its importance in sticking closely to the data. I followed this process to

structure the thematic analysis. Other authors have mentioned use of similar approaches in thematic analysis of qualitative data (Ritchie, 1994; Aronson, 1994).

3.6.3.2 Interviews with key stakeholders and focus group.

As for interviews with key stakeholders and the focus group from palliative care staff, I used framework analysis to establish themes. Framework analysis is reported as a more recent approach to qualitative analysis gaining popularity in health care research (Lacy, 2007; Krueger, 2000). This particular approach of analysis is suitable for analysing interviews especially in the context of applied policy research focused on providing strategic recommendations (Richie, 1994; Lacy, 2007). This important feature made this approach suitable for analysing this data.

After all digitally-recorded interviews and the focus group were transcribed; I spent time listening to audio records and reading all verbatim transcripts to check for completeness of data. Through studying transcripts, I became aware of key issues that arose from participants. These issues helped me to make judgement on relevance of data in relation to research questions/objectives (Ritchie, 1994). The process of making connections between the data and research objectives continued until research objective: *'to develop understanding on broader perspectives and the concept of palliative care in Uganda'* had been addressed as far as possible from the data available.

The process of analysing the data involved identification of sections or portions of data that corresponded to a particular theme. Making written notes on the transcripts helped to make it easier to identify data and link it to the theme. I then finally lifted specific pieces of information and placed it in thematic charts (Ritchie, 1994; Read *et al.*, 2004).

An example of the analysis in the form of an extract from a case chart is shown in figure 3.11.

Figure 3.11 An example of how case chart used for framework analysis

	Cases	Case 1 (K1 03)	Case 2 (K1 04)
Theme: Palliative care policies and advocacies	<i>Palliative care policies and advocacies</i> Data from specific portions in texts as follows (8:24,12:6,13:19,11:7, 8:19, 6:1, 5:20,10:11)	<i>It's currently in their Health Service Strategic Plan, in the HSSP..... So the policies are there, and once there's policy that means that the Ministry of Health will make it a priority, and it means that they should put funding available. Page 8 Line 24</i>	<i>I guess the other issue is that there's so little research into palliative care in Africa. When we're fighting competing funds there's very little evidence to demonstrate that palliative care makes a difference in Africa. There is in the rest of the world. In Africa, it's very difficult to demonstrate using data that palliative care is important Page 12, line 6</i>

3.6.4 Validity and reliability: Mixed Methods Research.

Whilst in quantitative research, the term 'validity' has been widely accepted; this is not the case with qualitative research. The term 'validity' has raised more debates in the context of mixed methods research (Onwuegbuzie & Johnson, 2006). It is acknowledged that in mixed methods research the use of qualitative and quantitative approaches makes assessing validity complex (Tashakkori & Teddlie, 2003; 2006; Onwuegbuzie & Johnson, 2006).

Authors have acknowledged that assessing validity in mixed methods research is attended by problems of integration and representation (Onwuegbuzie & Johnson, 2006), however, making claims supported by inferences which are dependable, confirmable, credible and trustworthy (as described in section 3.6.5) enhances validity of data obtained.

Below, I elaborate on two approaches used to assess validity in quantitative and qualitative aspects of this study.

3.6.4.1 Quantitative perspective: validity and reliability

The quantitative aspect of this study only involved patients and care givers who were required to report their experiences using an instrument: APCA POS tool. It is fundamental to this study that the instrument used was validated and recommended for use in Uganda study (Harding, *et al.*, 2010).

Cook and Campbell (1979) define validity as the best available approximation to the truth or falsity of a given inference, proposition or conclusion. In relation to APCA POS tool validation, it means the degree to which the instrument accurately and reliably measures what it intends to. APCA tool used was checked for validity by Harding et al (Harding *et al.*, 2010). Uganda is one of the African countries which APCA POS validation was undertaken.

Reliability is defined as consistency of measurement, or the degree to which an instrument measures the same way each time it is used under the same condition with the same subjects (Shadish, 2001). There are two ways that reliability is checked: test/retest and internal consistency (Shadish, 2001). The tool used was also checked for retest/retest and internal consistency by Harding and his colleagues (Harding *et al.*, 2010). In this study, further steps were undertaken to minimise errors, for example, the data were double entered, checked and inconsistencies corrected.

3.6.4.2: Rigour and trustworthiness: Qualitative perspective

There are a number of frameworks for assessing rigour in qualitative research but I have chosen one: Guba's (Guba, 1981; Lincoln, 1985) framework for ensuring trustworthiness in qualitative research. It has been suggested that judgement of the trustworthiness rests upon an assessment of the evidence that the research presents and whether a clear exposition of data collection process has been achieved, allowing readers to evaluate the claims made (Shenton, 2004). Guba (Guba, 1981) proposed that four criteria should be considered in assessing trustworthiness:

1. Credibility
2. Dependability
3. Transferability
4. Confirmability

First, credibility involves establishing that qualitative results are believable from participants' perspectives. In relation to my study, I aimed at using member checking or respondent validation which has been suggested as one way to enhance trustworthiness (Shenton, 2004). However, I did not have sufficient opportunity to present transcripts to be reviewed by research participants due to logistic reasons, though, I had the chance to check the accuracy of data which happened 'on the spot' in the course of dialogue and also at the end of interview.

Second, dependability emphasises the need for researcher to account for the whole process in which research took place for instance describing context, any changes that occurred and how that affected the way or manner in which research was conducted.

Thus, it has been suggested that qualitative researchers should emphasise the embeddedness of research data and circumstances of their production. In order to address the issue of dependability more directly, it has been suggested that the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work (Shenton, 2004). Hence, there is a need to describe clearly how the research design was planned and implemented, operational details of data gathering and to maintain a process of appraisal so as to evaluate the effectiveness of process of inquiry undertaken. For instance, using reflexivity: taking account of researcher's own biases, recognizing values and prior assumptions enhances validity (Lincoln, 1985).

I critically scrutinized my role as a nurse, researcher and as an insider on the research process and setting. I also described how I made meanings or sense of my own experiences during the field work (see chapter 4, 3.3.4.4. & 3.4.4.1). While reflecting on the data collection process and interviews, I also aimed at describing limitations I encountered so as to enhance understanding of context of process and data obtained. I have demonstrated openness through describing how I handled the situation where my own assumptions were challenged. For instance, my original assumptions as planned before going to the field were to interview each research participants individually, which was not the case when I carried out the study since some preferred joint interviews. I have discussed these specific aspects in detail (see section of interviewing). In addition, the pen portraits (*in chapter four*) and the reflexivity section helped me to gain understanding into experiences of participants. Further, pen portraits helped to detect the underlying influences and pattern of association and linkages of data in the following chapter (*chapter 5*).

Qualitative researchers have suggested that the rigour of qualitative studies can be realized through enhancing dependability and credibility amongst other elements (Silverman, 2001; Shenton, 2004). Consistent with this suggestion, I aimed at presenting sufficient data or evidence to support every finding presented. I have also described in detail the implementation process of the study during the different phases and further described the processes by which findings were derived from the data. As reported, when seeking to demonstrate that conclusions are justified, researchers should display enough data to permit an assessment of whether analyses used are indeed supported by data (Shenton, 2004).

To ensure rigour, I also enlisted the help of a competent peer review from experts in the field of palliative care in sub-Saharan Africa. In addition, meeting with experts in an international conference (6th EAPC research congress) gave me an opportunity to discuss in details my research. I encountered with established researchers from African palliative care association based in Uganda, whose contribution together with one national leader of palliative care Kenya enhanced credibility of study. In their observations and discussions, they posed important questions on areas such as research questions, methodology and data/findings.

I also had opportunity to discuss my work in international conferences where expert researchers in the field of palliative care in sub-Saharan Africa had chance to critically review my work and ask valuable questions. Particularly, inputs and contributions of Professor Irene Higginson, head of department, palliative care, Kings College London and Professor Scott Murray, head of the primary palliative care research in the Centre

for Population Health Sciences at the University of Edinburgh, enhanced the trustworthiness of this study.

Third, to address the issue of confirmability, my supervisors had an opportunity to critically examine and '*audit*' my work from initial stage of presenting original transcripts and all documents used for analysis. Development of units and themes were first shown to my supervisors in a practice consistent with what other qualitative researchers have recommended (Lincoln and Guba, 1985; Patton, 1990). To enhance confirmability, the study was also designed in such a way that it included more than one method to collect data, which although it does not meet the technical definition of triangulation (Lincoln and Guba, 1985), it provided rich data and multiple perspective of experiences

Finally, to address the issue of transferability, I have endeavored to give explicit and sufficient details following the principle of *thick description* (Lincoln and Guba, 1985 Shenton, 2004). The principle of thick description is reflected in the manner in which I have described procedures, steps and research processes, as well as the context of the study, to enable the reader to assess the extent to which the report of the findings can be transferred to other situations. In addition, the sampling strategy ensured that the study focused on the phenomena of interest in a detailed and sustained manner, providing adequate data with which to explore the research objectives.

3.7 ETHICAL ISSUES

Ethical issues were paramount in this study and were addressed to ensure that patient's rights were safeguarded and protected. Before conducting research approval was sought from Hospice Africa Uganda (HAU) and Uganda National Council of Science and Technology (UNCST) (*see appendix I*). A copy of research proposal also was sent to Aga Khan University-Kampala campus for peer review.

In the study, I took necessary steps to ensure that there was no harm to participants given their vulnerability state. One of the strategies I took to overcome vulnerabilities was to include third person preferably health professional in assessing patient. I also emphasised voluntary participation together with informed consent.

The sensitive nature of the research was discussed with the participants in advance. This approach was observed in the study by Cowley (2002) which gave an opportunity to discuss any concern and whether there are any difficulties. Other studies have documented the same approach (Gregory *et al.*, 1997, MacLean *et al.*, 2004).

All interviews took place in convenient location and time chosen by participants; however, it promoted privacy and confidentiality. The second round of interviews and administration of questionnaires, the research was conducted in patient's home. Whilst this may not facilitate privacy from carers (Beaver *et al.*, 1999), it ensured privacy from others, which may not be found in a public place. In this study however, it was anticipated that the presence of carers (family members) would affect the

quantity and type of discussion about the family members who care assuming the family members would be with the patient. Permission to conduct the interviews and administer questionnaires in the first phase (subsequent rounds of home visits) in the participant's home was asked before each visit

Gaining consent from staff and patients with advanced AIDS was completed prior to the commencement of research. This was on individual basis. All the respondents were assured of the confidentiality of the information they provided and that their participations were entirely voluntary and they would withdraw at any time.

3.8 DISSEMINATION

The key findings of this study have been presented in local and international conferences (see page iv) and part of the work was published in Palliative Medicine journal (Too *et al.*, 2010). It is expected that the findings of this study will be read by wider population of the academics, professional bodies and researchers in Africa and other continents.

The following chapter sets background of the findings of the study. It gives general understanding of the study-participants in phase one study.

CHAPTER FOUR

PARTICIPANTS

4.0 INTRODUCTION

A total of 30 patients with advanced HIV/AIDS (stages III and IV) were enrolled for the longitudinal study. This chapter gives a brief overview of each participant in this study, by use of a descriptive 'vignette'. These vignettes are a composite developed on the basis of data gathered from each person; subsequent chapters explore the issues raised in more depth. This chapter offers an initial introduction to the challenges and experiences encountered by PLWA in this study and their caregivers (family members) through depiction of what might be referred to as a 'journey of living with HIV/AIDS'.

4.1 AGABA

Agaba is a 40-year-old single mother fighting an advanced stage of HIV/AIDS singlehandedly. A former sweets-peddler (commonly referred to as 'jua kali' business market in Uganda), she is a lonely woman without caregivers, who is now bedridden. She is forlornly struggling to survive with an incapacitating fungating wound due to

KS¹¹ in both her lower extremities. She is in poor living conditions with poor housing facilities, and a poor drainage and disposal system. Too incapacitated and debilitated to shop for household items, Agaba now relies on her neighbours (fellow tenants) for her basic necessities, including food, but often the help she needs is not forthcoming.

I recruited Agaba when she was newly enrolled at HAU. She lives very near to the Hospice. She struggled to walk since her legs were severely affected. I undertook the first POS interview with her at HAU and was able to complete the second, third, fourth and eighth in her home. I went to her home with Hospice staff for translation purposes. In my first interview, Agaba was in severe pain and unable to concentrate. In the second and third POS interviews, she was able to concentrate because she had been started on morphine immediately. During my fourth POS interview and qualitative interview she talked freely as I had created a good rapport with her. I only noted that she expected a lot from me but I clarified my role as a researcher and referred her to Hospice staff for more information on her many needs. Fortunately, HAU enrolled her on the support kitty, which provides food and money for transport to access medical facilities in case of emergencies or to access drugs/medication.

4.2 DDAMBA

Ddamba is 45-years-old and married with three children. His wife is also infected with HIV/AIDS and now both fight a terminal illness together but have not disclosed their status to anyone except their health care workers. The children keep wondering why

¹¹ Kaposi's sarcoma: an HIV/AIDS-related cancer, which manifests in the advanced HIV/AIDS stage causing a lot of pain.

their dad is not able to go back to work as a truck driver or take them out to swim at Lake Victoria's beach. Ddamba has co-morbidity of Pulmonary Tuberculosis (PTB), an opportunistic infection which is being treated. Ddamba is on stage IV classification of HIV/AIDS and has KS.

I recruited him into my study when he was newly enrolled into the palliative care programme. In the first interview, Ddamba was happy to meet with me. He explained his condition to me and was happy to participate in the study. I followed Ddamba for eight weeks successfully.

On the second POS interview, the couple were excited to see us in their home. I was in the company of staff from HAU during the second round of visits. I learnt to build and maintain a rapport with the couple. In the third week, Ddamba came to HAU for the third POS interview.

During the qualitative interview, he was looking tired. I noticed that he was exhausted from seeking help from his friends. It was emotional interviewing this couple who did not want me to separate them. Ddamba portrayed a lot of dissatisfaction and resentment over unaccomplished plans and his state of helplessness and incapacity. He and his wife shared in-depth information without any reservation. I felt that I had managed to sustain the relationship with the couple. Ddamba described how they had not disclosed their status to anybody, even to the neighbours. They were careful in the way they related with their neighbours so as to keep their status to themselves. Changes in the appearance of their bodies were a major concern and, as Ddamba and his wife grew thinner and emaciated, they said that they did not want to move about in order to avoid being seen and then stigmatised.

4.3 KIBUUKA

Kibuuka is a 43-year-old Ugandan man, with five children, though not living with him. He had been separated from his wife for a long time but his wife had returned to take care of him once he became bedridden. He is fighting loneliness and has advanced HIV/AIDS (stage IV) and a fungating wound in his leg due to KS. Kibuuka was suffering from excruciating pain due to the KS. He is unable to walk and is receiving home-based care. He had been on HAART but at the time of the interview the drugs had finished and he was not receiving any treatment. He lives in a mountainous, muddy, hard-to-reach area in a small unfurnished house. It is difficult for a palliative care team to access him. In his interview he expressed a sense of abandonment and a lack of basic facilities and money.

In the first POS interview, he was very depressed and in pain. He was cooperative and responded to each question well. I recruited him to this study when his wife brought him to HAU for palliative care intervention. After I recruited him, he was not able to find support to enable him to come back to HAU and because he was bedridden. I therefore followed him at home for all POS interviews and the qualitative interview. Kibuuka looked sad during the interviews, having been deserted by his family. He looked emaciated and weak. His wife visited him occasionally; I was unable to establish the cause of their separation. It took me hours to locate where he lived but finally found his house located in a bushy compound looking neglected. I found Kibuuka and his wife sitting on a mat on a crammed floor waiting for me. They offered me a mat to sit on the floor. We did the interviews in a tiny unventilated room

which served a dual purpose: lounge and bedroom. When I asked him questions about his illness, he shared his difficult times about suffering a lot from pain and lack of treatment and support. I felt sympathy for him when he described his experience of stigma, separation from his wife and lack of treatment because of lack of money and his living conditions.

4.4 MANGENI

Mangeni is a Muslim polygamist woman aged 47, whose husband died of HIV/AIDS; she now has advanced HIV/AIDS and is bedridden. She is currently being taken care of by her daughter-in-law. She is living in a semi-finished house in a mountainous and inaccessible area ten miles away from Kampala.

I recruited Mangeni and administered the first POS interview at HAU. During her first week she was wheelchair-bound. The subsequent POS and qualitative interviews were administered at home because she could not get out of bed. During the first interview, she was relaxed but after the interview she asked me how the issues she was worried about could be resolved. I explained my role as a researcher and referred the matter to Hospice staff for further assistance. Mangeni was referred from the HAART centre in Entebbe to seek palliative care from the Hospice for pain and symptoms which distressed her. I noted that Mangeni was angry at even small happenings. I tried to understand her anger and approached questions with sensitiveness. She was ready to share her experience(s) of living with HIV/AIDS. I felt that I needed to sustain the trusting relationship since she had not fully disclosed her status to everyone in the family. Mangeni was deeply rooted in the Muslim culture. In the second POS

interview, she seemed to still have had psychosocial problems as well as physical problems which she wanted to share with me. Initially she was disturbed a lot by diarrhoea and was looking dehydrated but I noticed much improvement on the fourth and eighth weeks. In her fourth and eighth POS interviews she was able to concentrate more than before because Hospice staff had intervened to relieve some of her distressing symptoms. I learnt from this interview that caregiving to bedridden HIV/AIDS people in an advanced stage is quite challenging for the caregivers. Mangeni's caregiver was at risk since she used bare hands to clean discharging wounds and soiled clothes.

4.5 MUSOKE

Musoke is a 25-year-old single male high-school student. He is the third-born in a family of five. Musoke dropped out of school under the influence of drugs and peer pressure and ended up as a street boy in one of the towns in Western Uganda. After leading a wretched life for two years on the street and involved in drug abuse, he went back home and decided to go back to school. Then Musoke first noticed a KS ulcer in his left toe before thus discovering he had HIV/AIDS which was already advanced. His mother took Musoke to hospital for management; he then went to live with a relative in Kampala while accessing treatment.

I recruited Musoke on the first day that he was enrolled into the palliative care programme in HAU, and administered the first POS interview. He talked freely during the interview session and was ready to share his experience after I explained the purpose of the study. I successfully followed him up for eight weeks.

He was trying to rehabilitate from drug abuse and had just started taking HAART. At the time of my second interview (POS), Musoke experienced breathlessness and was hospitalised. I rescheduled another time to interview him since he was very anaemic and was on a blood transfusion.

During the qualitative interviews at home, he was not comfortable having his mother around. I therefore organised a convenient and confidential room to carry out interviews. He warned me that the neighbours and other people thought that he suffered from cancer and not HIV/AIDS; he had not disclosed his status to anyone except his mother. This implied to me that he feared the HIV/AIDS stigma. In the beginning of the interviews, he was brief in narrative but after encouraging him he was able to talk more freely and was relaxed. I learnt that I needed to be sensitive and ask questions in a more open-approach manner and not be so specific. He finally described how KS in his left foot had disturbed him since he cannot put on shoes nor walk. He further responded to each question I asked him; I clarified questions that were not clear to him. This particular participant was interested in my study and kept all appointments.

He was started on morphine and in a few days he had his pain controlled. I made contact in the fourth week with his mother to get her views about receipt of palliative care. Apparently, Musoke had resumed to 'normal' life and was working in a workshop, though not doing heavy duty but light jobs to keep himself busy. I noticed that he had improved following his pain and symptom management. Musoke warned me that I should keep the diagnosis secret and not to disclose to anyone in his area of work (workshop). I noticed that he feared being stigmatised as he preferred to tell his

colleagues that he suffered from cancer only. Upon reflection, I felt that Musoke feared losing friends and was worried about the ways the community would see him.

4.6 NABUKWASI

Nabukawasi is a 31-year-old single mother in an advanced stage of HIV/AIDS. She has one daughter aged 15 years. She is the second-born in a family of five. Nabukwasi is hospitalised frequently because of her overwhelming symptoms of breathlessness and severe anaemia. She had just completed a blood-transfusion and was bedridden; she moved around using a wheelchair. Nabukwasi was lonely as the result of family abandonment and had been selling all her personal property in order to pay for transport and hospital bills. Nabukwasi warned me to keep the diagnosis from her daughter and any of her family members. Her daughter came twice in a week in the evening from school to take care of her mother, a demanding task for a full-time schoolgirl; before long she dropped out of school due to lack of money to pay fees.

I recruited her and administered the first POS interview during her first day at HAU. I successfully followed her in the study for eight weeks. I did the qualitative interview in the fourth week. During the interview, she was anxious and breathless and was very sensitive with information. She was typical of those who had not disclosed to anyone. I observed a difference in the manner she talked when others were present, like her daughter; she would hide some information and keep silent for most of the time. With this, I knew I needed to win her confidence through assuring her of anonymity and discussing her experience in a convenient location which was acceptable to her. During the qualitative interviews, I secured her a confidential room

in the hospital and wheeled her there; she then talked freely and more openly. I learnt that she treasured secrecy and confidentiality a lot. I learnt to clarify the question and response in order to get the right information. When she recalled her experience of previous hospitalisation and disposal of her assets, she could not resist tears and lamented her loss. She kept referring to her daughter who had nothing left for her inheritance because all her property had been auctioned to raise money to pay bills. She wished she would die to avoid being a burden. She looked to me as if she had lost hope in life, and her family had neglected her. She was infuriated by the fact that her daughter was unable to continue in school because a certain relative who had been supporting her was no longer willing to continue.

4.7 NANKOMA

Nankoma is a 39-year-old widow who is bedridden with advanced HIV/AIDS. She also suffered from co-morbidities which include PTB and KS. She is on treatment: HAART. She was frequently hospitalised due to her breathlessness. Further, Nankoma suffered from painful fungating wounds in the feet due to disseminated KS. A young girl was her primary caregiver and played an important role in encouraging Nankoma to take medication and supporting her emotionally.

In the first POS interview with Nankoma, I found she was quite distressed with difficulties in breathing. She was sweating, emaciated and very weak to even talk. I contemplated postponing the interview to allow her to get better. I had gone there with Hospice staff to interpret for me and so the staff intervened first. After a while, Nankoma was able to talk to us in an interview that lasted for 15 minutes. I learnt to

be patient and sensitive to the needs of the patients before carrying out interviews. I observed the disillusioned role of the caregiver since the girl was not strong enough to meet Nankoma's demands and needs. The caregiver was observed breaking into tears as she explained circumstances under which she tried to give support to the patient. I observed with sympathy, that the young girl was psychologically drained and tired of taking care of a dying patient who was breathlessness. I could not interview the caregiver since she was below 18 years. Nankoma was hospitalised most of the time for oxygenation and so did not stay at home for long. Unfortunately, when I tried to contact her for the eighth week POS interview, I was informed that she had died in the hospital in the seventh week after joining the study. On reflection, I felt that neglect and lack of support influenced her frequent hospitalisation. It was notable that she preferred to stay in hospital rather than at 'home' since she had the assurance of support from hospital staff and also for emergency intervention of her breathlessness.

4.8 SSEMATIMBA

Ssematimba is a 44-year-old polygamous man, who lives with his younger wife and his children. He is in an advanced HIV/AIDS stage (stage IV) with opportunistic infections. He also has KS in his hands and body. His CD4¹² count of 112 and so was started on HAART. He is getting home-based palliative care in his rural home five miles away from Kampala City. His main caregiver is his wife who always

¹² CD4 used to help evaluate and track the progression of HIV infection and disease. CD4 cells are the main target of HIV, and the number of CD4 cells will decrease as HIV progresses. A normal CD4 count in a man without HIV infection will be approximately 400 to 1,200 cells per cubic millimetre of blood.

accompanies him since he is unable to move on his own. He is looking dehydrated, weak and emaciated.

I recruited Ssematimba for the first POS interview when he was newly enrolled into palliative care at HAU. He had difficulty walking as he was very weak; he was in the company of his wife. During the first day of the POS interview he was in very much pain due to KS in the hands and body. He reported that his hands had become so rough that he looked like someone with leprosy. He came into the Hospice with his hands and most of his body covered with heavy garments/jackets and so one could not witness his discharging wounds. On reflection, I think he did so to avoid the stigma associated with HIV/ADS since he was using public means to get into the Hospice. During the interview, he allowed his wife to be present. He then excused her and went on to share his experiences of having HIV/AIDS and the associated challenges. I kept clarifying questions with him since he looked as though he had hearing problems. He looked so hungry and thirsty and was offered with a drink in the middle of the discussion. I did the second, third, fourth and eighth POS interviews at home since he had difficulty getting transport to the Hospice. On the fourth POS interview, I conducted a qualitative interview in which Ssematimba shared his experience of feeling better since being enrolled for palliative care intervention at the Hospice. He kept referring to a lack of basic necessities including transport, food, money and good housing. He mentioned land and other assets that were sold to pay hospital bills for family members who have been in and out of hospital for treatment. Having more than one wife and HIV/AIDS was draining his resources and I noticed that the family had spent a lot of money in the hospital. I could not establish clearly how many of his relatives were suffering from HIV/ AIDS since Ssematimba was not ready to disclose.

4.9 KISOMOSE

Kisomose is a 48-year-old Ugandan man. He has no other known family members. He was brought to hospital for resuscitation after he collapsed in an unidentified location. He is in advanced HIV/AIDS stage IV with several co-morbidities including KS. He had fungating wounds in his legs and PTB. His fungating wounds were strikingly astonishing. He looked as though he had elephantiasis but it was KS which had infiltrated into all tissues and was now very painful and oozing. Maggots were seen in his discharging wounds which seemed to bother the adjacent patients. He lacked food and general basic facilities, including toiletries. He relied on Good Samaritans to survive. Quite often the relatives of adjacent patients who knew him brought him some drinks or snacks as he was abandoned and neglected. Some church members and volunteers took an interest and were seen to be helping him in shifts. He was soon breathless due to anaemia, which was related to food deficiency, and he was transfused but it did not help; his condition worsened each day.

I recruited him and administered the first POS interview at the hospital where he was receiving treatment. At the same time, he was enrolled into new services of palliative care. During the interview, I was with hospice staff who helped in translation. He looked so very emaciated with a very old looking face. He did not mind conducting the interview while he was in the bed, but I screened his bed to give him some confidentiality and privacy. Because of his weakness the qualitative interview did not last long. He described how biting hunger and lack of basic necessities were painful experiences and he said that he wondered why he was still alive. The Hospice had offered him help with food and treatment. He was started on morphine immediately.

During my third and fourth contact with him, he was able to concentrate and express himself in a relatively relaxed manner in comparison to the first contact I had with him. However, I observed that he suffered from a gross lack of basic necessities, like food, and emotional and psychosocial support, which made him look withdrawn and depressed. He did not stay long in the hospital, and died shortly after I carried out the qualitative interview. I could not get his eighth week POS interview.

4.10 MUGUME

Mugume is a 45-year-old married man. He lives with his three boys in Kampala. He is a refugee from the Democratic Republic of Congo, which had recently had civil wars. He is being taken care of by his 13-year-old son who left school to take care of his ailing father. Mugume has advanced HIV/AIDS stage IV with KS on his body. He has other co-morbidities including oral thrush, which affects his eating. He looks very dehydrated, wasted and skeletal. He is on HAART and being treated for multiple medical conditions and for symptom management. He is bedridden and so entirely depends on the young boy for all his personal care. I felt the boy was frustrated, tired and disillusioned in his role as he was not strong enough to meet his father's demands and needs. He wore 'kanzu', which is typical attire for the Muslim community.

I recruited him and administered the first POS interview as soon as Mugume was enrolled into new services by the Hospice. He did not have any difficulty completing the POS interview. The only concern was his chronic diarrhoea; this distressed him and interrupted our discussion. During the interview, he would tell me to understand him when he has to end the conversation suddenly due to distressing symptoms.

During the second POS interview, his pain and these distressing symptoms had improved and he was able to talk to me freely without too much interruption. He asked me whether I knew what can be done for him to get better since he claimed that he had visited all health specialists in vain. I explained my role as a researcher and referred him to other health care workers and Hospice staff to explain the kind of care and treatment he needed.

He died in the third week before the third POS interview due to complications related to advanced HIV/AIDS. I was so shocked to lose him since to me he appeared to have been getting better. It appeared to me that the end-of-life care he received in his last two weeks added to his quality of life and reduced his suffering.

4.11 NABULUNGI

Nabulungi is a 47-year-old lady who is divorced and now lives with her daughter. She is in advanced HIV/AIDS stage III but is not on HAART. Nabulungi is living in a semi-urban area in Kampala. Though she was bedridden, she was not hospitalised; she received out-patient services for her condition. The daughter reported that it was Nabulungi's preference to stay at home. Nabulungi appeared small and skeletal. Her health was deteriorating and she appeared to have distressing symptoms which needed acute management.

I recruited her and administered the first POS interview on the first day she was brought to HAU. Though she was willing to talk to me, she was weak and I did not want to keep her for long. As soon as I completed the first POS interview, I scheduled

to meet with her the following week. I succeeded in visiting her at home and completed the second POS interview.

During the second POS interview at home, she welcomed us though her voice was too low and weak. She asked the daughter to prepare for me a soft drink. Before the end of the next week she died of complications related to HIV/AIDS.

4.12 NALONGO

Nalongo is a 29-year-old single lady living with her elder sister. She has advanced HIV/AIDS stage IV and is on HAART. She is emaciated and appears to be almost too weak even to speak. She has opportunistic infections and PTB. Nalongo is in an acute ward in the hospital on oxygen and receiving treatment for symptom management. She has been in and out of hospital due to the critical state of her condition. KS on her body pains her so much, as is evident in her discussion.

I recruited her and administered the first POS interview on the first day she was enrolled into new services at HAU. This particular patient was not easy to deal with it because she was so weak and distressed to such an extent that talking was a stressful event. My observation of her condition necessitated that I find out her view about carrying out an interview. She accepted to be enrolled into the study and only cautioned me not to take long as she wanted to rest. Finally, I administered the POS interview which took a short time and I scheduled another appointment.

During the planned second POS interview she was too weak to talk. She was on oxygen on and off. Clearly, her condition was getting rapidly worse, so I left her to

rest and booked another time with her. I promised to check on her each day (through calling caregiver/sister) until such a time when she would be relatively better to talk to me. Little did I know that my contact with her was the last opportunity of meeting; she died as soon as I left hospital. It was sad and I was emotionally disturbed by her death when I heard of it. This was the sixth person who had died in the research and I felt sad, and also worried that my research would soon come to an end. I echoed my fears and anxiety to my supervisors; they advised me to keep the data of all those individuals who died during my research and continue, as these deaths were to be expected among people with advanced HIV/AIDS stage IV who were my target population. This allayed my fears. I continued to meet challenges of attrition but I promised myself that I would not let go of my determination and would complete the research study.

4.13 SALONGO

Salongo is a 33-year-old single man. He is living with his sister in Kampala. He relocated to Kampala in order to access treatment and management of his advanced condition. He is in advanced HIV/AIDS stage III and is not on HAART. He had other co-morbidities: KS and squamous cell carcinoma on his mandibles. His inability to eat or drink was his major problem and concern to health care workers. He received outpatient services from both hospital and Hospice. Although he was still able to walk, he was not able to do so for very long.

I recruited him and administered the first POS interview on the first day he came to HAU. During the interview, a HAU staff member was present for translation. Salongo

experienced problems in expressing himself due to the cancer which affected his mouth and jaw. This meant it was challenging to interview him. The sister explained most of the issues relating to his condition during the interview.

During the second POS interview, he looked very ill and his condition was deteriorating, which I attribute to having not started HAART in good time. However, when he did start, it appeared he suffered from IRIS,¹³ and he subsequently died before I was able to talk to him about his experience of living with HIV/AIDS.

4.14 SSEMWANGA

Ssemwanga is a 43-year-old polygamous man. He usually lives in a rural area with his wives and 12 children but relocated to stay with his relative in Kampala in order to access treatment. He is in advanced HIV/AIDS stage IV and is on HAART. Ssemwanga suffers from pain and distressing symptoms including breathlessness. One of his wives has HIV/AIDS, but I could not establish whether his other two wives had contracted the deadly disease. He was always accompanied by the wife who now is in HIV/AIDS stage I (asymptomatic).

I first met Ssemwanga in the cancer ward in the national referral hospital when HAU enrolled him into new services of palliative care. I recruited him and administered the first POS interview on the second day after he was admitted into hospital for

¹³ Immunological-Reconstitution Inflammatory Syndrome: another new disease entity following treatment initiation of HIV. It is a new syndrome of lipodystrophy as a long-term complication of HAART. It was found to be a direct toxic consequence of the various drugs used in combination regimens (HAART).

management of breathlessness. He was in a distressed state the first day and could not concentrate: I therefore arranged to meet with him the following day, when I was able to administer the POS interview.

During the third POS interview he was looking very ill. He had not eaten food for some time, and had diarrhoea and severe dehydration. He died in the following week before the fourth POS interview and the qualitative interview.

4.15 ZILABAMUZALE

Zilabamuzale is a 60-year-old married man who is a farmer. He is breathless and bedridden; being unable to walk. He is very weak and depends on other family members for daily needs. He lives with his wife who is also infected with HIV/AIDS (stage II). He is a father of five children (two sons and three daughters). One of youngest children died of HIV/AIDS. He is in an advanced HIV/AIDS stage with KS with opportunistic infections. He has been on HAART now for six months. He is frequently hospitalised for oxygenation.

I recruited Zilabamuzale the first day he was newly enrolled into the palliative care programme at HAU. He reported that he was in severe pain, which had caused him sleepless nights. By the time of the second POS interview, he had been started on morphine. I succeeded in following him and was able to administer the first, second and third POS interviews. I was unable to engage him in a qualitative interview as he died in the fourth week. He received joint home-based care: The AIDS Support Organization (TASO) and HAU.

4.16 AMANDUA

Amandua is a 20-year-old orphan boy who, at the age three, lost his mother due to HIV/AIDS, and was subsequently brought up by a neighbour (Good Samaritan). He has lived with the HIV/AIDS virus for 20 years until he defaulted on HAART for six months and his condition started to deteriorate. When I met with Amandua, he was unable to walk due to KS on his right leg.

I recruited Amandua who had advanced HIV/AIDS (stage III) the first day he came to HAU. In my first POS interview he was very anxious and feared death. He had been persuaded that he had been miraculously healed through prayers; this partially contributed to his defaulting on HAART. He perceived palliative care to quicken his death and so preferred alternative care. The first day I met with Amandua, it was clear that he was ignorant of the KS symptoms as he complained of symptoms like ‘chicken pox’ which disturbed him a lot. Further, he was ignorant of MTCT¹⁴ as he kept wondering how he got the HIV/AIDS virus. I noted that Amandua was greatly concerned with his physical changes, self-image and perceptions. He wished that did not have the wasting syndrome which was stigmatising and associated with being close to death. During my initial contacts at the Hospice, Amandua shied away from discussions of palliative care but later on was helped by Hospice staff to accept the diagnosis. I felt that Amandua was sweating during my first interview and was looking nervous and withdrawn. I felt that asking him to ‘Tell me more about your illness’ was more intrusive as he had not fully accepted the reality of living with HIV/AIDS. On reflection, it gave me insight of how to frame sensitive questions,

¹⁴Maternal-to-Child Transmission of HIV/AIDS Virus.

especially to teens living with HIV/AIDS. I noted that Amandua had a lot of challenging unanswered questions in his mind related to psychosocial and physical wellbeing. Further, I observed that he was not able to express himself well in the presence of his 'guardian'. I therefore planned to interview him alone at HAU and he was thus able to open up a bit more freely. I learnt to cultivate a trusting relationship and the importance of creating a conducive, confidential environment.

4.17 GWANDOYA

Gwandoya is a 32-year-old polygamous man with advanced HIV/AIDS (stage IV), living with his wife who is in HIV/AIDS stage II. He had a CD4 count of 13 and looks very emaciated and very weak. His first wife died of HIV/AIDS and now he has infected the second wife with the HIV/AIDS virus. Two children died of HIV/AIDS and now they have two children with the last born being infected with the HIV/AIDS virus. He lives in a semi-urban area receiving both home-based care and is frequently getting hospitalised in the cancer ward (in-patient).

I met Gwandoya for the first time at HAU when he was brought in by his mother. He looked very weak and walked with difficulty. I recruited him the first day he was enrolled and administered the first POS interview. He did not return back to the Hospice but I made successful contacts with him at home for the subsequent eight weeks. It was not easy finding him after he left the Hospice because he was frequently admitted to the hospital for management of opportunistic infections and also for his breathlessness.

During the interview at home, he was not comfortable to have his family members around him so we arranged to have a more suitable and convenient confidential environment. He accepted to share his in-depth experience of HIV/AIDS. I had gone with HAU staff who helped in translation. Gwandoya was happy to share with us his experience and his sharing focused on needs and challenges related to lack of support. I noticed that his mother was eager to share with us the experience of taking care of Gwandoya.

During the fourth POS and qualitative interviews, I noted that the mother had taken a more active role in giving care since his wife was poorly, weak and unable to support her husband. A faith-based organisation had offered to support Gwandoya's family and to educate his children, and offered partial aid to the family. Whilst Gwandoya was on HAART, his wife and young child had not yet started it. They relocated their residence to live near the faith-based organisation where they could get assistance.

During the eighth-week POS interview, I noted he had sold all his furniture to pay for his treatment and meet bills (rent, electricity and water) as well as to buy food. We sat on the floor to carry on with the interview, as the house was almost empty. I was emotionally affected to witness their lack of basic necessities.

4.18 LUTALO

Lutalo is a 38-year-old married man who has advanced HIV/AIDS (stage III). He is a long-distance truck driver and for several years he had been transporting goods across East African countries. Lutalo now lives with a new partner after his previous partner

left him. He has five children all together from his previous and current relationships. I could not meet with his family members because he had relocated to stay with his elder brother in Kampala who now gives him basic support and transport to access medical care in the city of Kampala.

I recruited Lutalo on the first day at HAU. He had disseminated endemic KS, which spread throughout the body. He was referred from the National Referral Hospital to the Hospice. He successfully completed the first, second, third, fourth and eighth week POS interviews. During the fourth week POS interview, I carried out qualitative interviews in his residence (brother's house). He was tired-looking and bedridden. He was ready to share his feelings and experience, though was a bit hesitant when his brother joined. I asked his brother to excuse us for a short while, which he accepted. I tried to win and maintain his confidence in me as a researcher. He was very talkative and sometimes I tried to echo the question in a slightly different way so as to reveal his life experience without necessarily deviating into a different topic. I could observe him struggling to express himself because of language problems, as he stammered at times. I then invited Hospice staff to help interpret some particular words so as to bring out the original meaning. I found that Lutalo's main distressing symptoms were chronic side effects of HAART resulting from IRIS, which happens mostly when HAART is started at an advanced stage of HIV/AIDS. Lutalo regrets having wasted a lot of money in using traditional Chinese herbal medicine before seeking medical health care since it did not help. I felt that his brother was stressed by Lutalo's condition and what his condition meant to him: shouldering additional responsibilities of taking care of Lutalo and his family.

4.19 KIZZA

Kizza is a 28-year-old father of three. He is a fisherman, a business he has engaged in for a long time. He was diagnosed in 2004 with HIV/AIDS but lived for some time without symptoms. However, by 2008, he was very ill but not in receipt of any treatment. His condition meant he had to quit fishing. His main problems were pain and symptoms associated with KS, and the fact that his first-born child, a girl of eight, was missing. Kizza explained that he believes that, because his symptoms were so dreadful, his elder sister perceived HIV/AIDS as equivalent to 'death' and so she came and took his daughter away. Kizza's wife is pregnant and they have two other children. He has not disclosed his status to his wife. Kizza moved to live with his sister in Kampala so that he could gain access to treatment.

I met Kizza at HAU and recruited him to the study. At that time, he reported suffering from pain from multiple abscesses in his left arm. He said that he had been cutting these with a knife before coming to the Hospice. He completed the POS interviews on weeks one and two at HAU, but was then too weak to come to HAU. I visited him at his sister's house to conduct the POS interviews for weeks three and four. I noted that the living conditions were deplorable and there was little space. Kizza, his sister, two of her children and one of his children shared two rooms. They were surviving on approximately Ugsh. 2000 per day (less than a pound) and one meal a day. The children looked malnourished, weak and listless; they often cried. The HAU staff who accompanied me to the house offered everyone snacks. On week four, Kizza agreed to take part in a qualitative interview, with HAU staff present to interpret. During the interview, Kizza's wife arrived unexpectedly. She was worried about an antenatal clinic report that she had been given, which provided a note of her positive HIV/AIDS

status. For this reason, I terminated the interview, leaving the HAU staff to manage what was a difficult situation. His experience showed some of the ethical issues involved in my research.

4.20 NABIRYE

Nabirye is a 24-year-old bedridden woman who was once married but is now separated from her husband. She is the second-born in a family of four, currently receiving home-based palliative care from HAU and frequently hospitalised due to chronic diarrhoea and severe dehydration. She has one child who is also infected with HIV/AIDS. Nabirye is fighting debilitating symptoms and her main concerns were the cultural and language barriers while seeking medical care. She preferred to be treated far away from home where no-one could identify her for fear of being stigmatised.

I recruited Nabirye during her first day at HAU. I administered the first POS interview and followed her up successfully for eight weeks at home. She focused her experience on psychosocial issues which affected her so much. She was frustrated by her inability to interact with health care workers and other people due to varied cultures and communication problems. Nabirye aimed to access medical facilities far from her home area because of her fear of being stigmatised. I found Nabirye quite depressed because she did not know what to do with her young child who also had HIV/AIDS. She described how distressing and disturbing the symptoms of advanced HIV/AIDS had been to her. She described how she would not be certain that the following day she would be at home or in hospital since she had chronic diarrhoea, which had made her severely weak and dehydrated. During her interviews, she looked very anxious

about her health and outcome of care. She narrated her experience of having to try anything to get better. I learnt from this particular participant that I needed to show sympathy to them and allow them to express their fears and anger. I felt that my questions were a bit closed in that they limited their views. I therefore learnt to ask more open questions.

4.21 NAFUNA

Nafuna is an 18-year-old girl who dropped out of school to get married. She now lives with her very old auntie after she could not be supported by her partner. She is the fourth-born in the family of an unknown number of children to her polygamous father. Because of the nature of the disease, Nafuna looked like an old woman, yet she was just 18 years old. Nafuna had to stay in bed most of the time. Since her auntie was very old and not strong enough to support her growing palliative care needs and demands, she relocated to an urban area (Kampala) to live in her brother's house where she could access treatment.

I administered the first POS interview to Nafuna and carried out interviews at home. I successfully made five contacts with her in a span of eight weeks. Her brother was instrumental in arranging for appointments to visit Nafuna. During the qualitative interview, Nafuna had a lot to share with me. She described problems and challenges she encountered in the rural areas where she lived with her auntie for a while. Her auntie was old and could not help her and so she fought distressing symptoms and painful wounds singlehandedly. She describes scenarios where she had dizziness and collapsed. Remarkably, Nafuna kept her diagnosis to herself and only confided to her mother at later stages. She responded well to my interview questions. At the end of the

interview, she was happy that I had shown a lot of interest in her condition. She seemed to me that she expected me to give her a lot of support after the interviews. I clarified my role as a researcher and linked her up with HAU for further information. She was hospitalised twice during the follow-up period.

4.22 OKELLO

Okello is a 40-year-old man married with three children. A Good Samaritan offered Okello and his breastfeeding wife accommodation while they sought medical care in Kampala. I found Okello four weeks after he relocated 200 miles in search of medical intervention after failure of the rural health facilities to attend to them. Okello was emaciated, dehydrated and bedridden, and weighing only 4.8 stones. He had pain related to KS in advanced HIV/AIDS. Remarkably, his wife was negative and this case study presents an experience from the discordant couple perspective

I recruited Okello in the hospital after HAU enrolled him into the palliative care programme. I administered the first POS interview to get baseline data. The poverty-stricken couple were asking me for help and expected a lot from me, especially after carrying out interviews. I observed the couple literally asking for help from anyone who crossed their way. On one occasion (the third POS interview), the couple were on the out-patient ward and were stranded as they did not have any means to get back to their accommodation. They were in a state of hopelessness and looked so depressed and tired. I must admit that it was emotionally draining for me to interview them as I felt as though they expected a lot from me, yet I could not do much for them. In my subsequent interviews, HAU had already enrolled Okello into the support kitty

programme, which supports poor patients. I therefore found Okello eager to meet with me in the second POS interview. Okello successfully completed the second, third, fourth and eighth POS interviews. In the fourth week's POS interview, Okello was able to give his life experience of living with HIV/AIDS together with his wife as the main carer in the qualitative interview. Okello talked slowly while narrating his experience. Whilst he could not remember some experiences, especially when he got HIV/AIDS, he dwelled a lot on the experience of stigma and lack of support. I found that it was helpful to ask probing questions relating to the areas they remembered. I found it particularly challenging to interview Okello in the hospital as there were a lot of other activities which kept disturbing Okello's attention: he was not relaxed and free to share his feelings.

4.23 MASANI

Masani is a 48-year-old woman who has been widowed twice. She has children from both husbands. Masani lives with a relative in an overcrowded slum on the outskirts of Kampala. The house was mud-walled with no furniture. I met Masani the first time when she came to the Hospice for palliative care. I enrolled her into my study and administered the first POS interview. I arranged to do follow-up interviews at home. It was difficult locating her residence, since there was much congestion and overcrowding.

I successfully administered the second, third, fourth and eighth POS interviews at home. I noticed that she did not interact with others well. She preferred to stay indoors, which I attribute to her deteriorating condition before she was started on

medical intervention. She described how her 'seemingly rotting leg', according to her, had produced a foul smell and how she was stigmatised for having a sexually transmitted disease. She had been traumatised by a poorly-managed STI (sexually-transmitted infection), which had now produced an awful smell.

During the interview, she freely talked while smiling most of the time; however, I could perceive that she was in great need. Masani was concerned about where I would sit and interview her as there was no chair, but I made myself comfortable in some little unoccupied space and sat. Some of the difficulties I experienced while interviewing included lack of adequate ventilation and light as well as space. Masani concentrated her story around the socio-economic impact of disease on her. I felt for her when she described her past experience when her boss chased her away from the work place because she had HIV/AIDS and because it was feared she would die on the premises. It was emotionally draining to interview Masani in her stigmatised, neglected and abandoned state. I witnessed her gross lack of food, basic household items like soap, paraffin and furniture.

4.24 ADONGO

Adongo is a widow, aged 44, with four sons and one daughter, who is the eldest. The four boys take care of her in shifts. She is bedridden with advanced HIV/AIDS stage IV, receiving palliative care in the home care setting. She was a midwifery nurse and had been working in one of the hospitals near Kampala until she became ill. She looked depressed and withdrawn.

I first met with Adongo at HAU when she came in for palliative care. I recruited Adongo the first day she was newly enrolled into the palliative care programme. She came in the company of her elder sister, who talked a lot on her behalf because Adongo kept quiet in most discussions at the Hospice. I administered the first POS interview at HAU and arranged to have follow-ups at home for the second, third, fourth and eighth week POS interviews. I successfully made weekly contacts with Adongo at home.

During the qualitative interview in the fourth week, Adongo said she was not willing to share much of her experience of living with HIV/AIDS. The elder daughter informed me that she has been like that for a while now and that we needed to give her some time. We casually chatted and, after a while, she began to talk. She preferred to sit on the mat on the floor, and so I chose to also spread a mat and sit on the floor while carrying out the interviews. I must acknowledge that it was not easy carrying out interviews with Adongo as she was so withdrawn and quiet. I used probing questions each time I asked her a question. She was only responding to my questions in a short and brief manner. The elder daughter helped me to elaborate some responses on her behalf. I would maintain some silence and would motivate her to reflect and share experiences; definitely, the approach worked better for me in the interview. I learnt how silence sometimes helped respondents to talk more. The daughter described how Adongo disclosed her diagnosis to the pastor and a few church members who prayed for her; however, she did not disclose to family members until later when she was hospitalised. I noticed that the boys had a challenging time taking care of their mum who was bedridden and depended on them for all personal care needs.

During the eighth week POS interview, Adongo was looking better and was able to smile and shared her positive experience of palliative care. She was more open and free to me during this last week. It appeared to me that I had developed and sustained a good relationship with her. She died not long after the end of the follow-up period.

4.25 MUGAGGA

Mugagga is a 31-year-old married man living with his wife and one child. He was a mechanic but now suffers from advanced HIV/AIDS stage IV and is on HAART. He also suffers from other co-morbidities; KS and opportunistic infections in the mouth and skin. He was in and out of hospital due to breathlessness. He has had general lymphadenopathy and is anaemic. He is dehydrated and wasted in a bedridden state. Mugagga was taken care of by his father while he was in hospital because his wife was ill with HIV/AIDS stage II and not strong.

I recruited and administered the first POS interview when HAU enrolled him into the new services. He was jointly managed by the Hospice and the National Referral Hospital in Kampala. I successfully administered the second and third POS interviews in the hospital but when I went back to see him the following week, I was told that he had left hospital. I was later told that Mugagga demanded to leave the hospital and go home while he was supposed to be still in the hospital. I felt that I had missed an opportunity to interview and record his experience of living with HIV/AIDS and especially his reasons for preferring to stay at home and die there. On reflection, I thought he must have got severely depressed and given up on life, a common phenomenon in the last days of patients with advanced HIV/AIDS stage IV.

4.26 NAKANWAGI

Nakanwagi is a 30-year-old married woman. She lives with her husband, who is in advanced HIV/AIDS stage IV, and three children. She is in advanced HIV/AIDS stage III and is on HAART. Both she and her husband, Ddamba, participated in this study as they both met the inclusion criteria. They live in a rural area away from Kampala but accessed out-patient services from HAU as well as home-based care. These particular participants had not disclosed to anyone among relatives or neighbours for fear of stigma. Experience of care for and by an HIV/AIDS partner was a challenging one to Nakanwagi. They lived in a semi-permanent structure and were unable to finish it because of their physical weakness. Nakanwagi is a volunteer at the community supporting initiatives that help PLWA.

I first met Nakanwagi at HAU when she came with her husband for palliative care services. I recruited her and administered the first POS interview. She was eager to discuss with me her condition but I clarified my role as researcher and promptly linked her up with Hospice staff who helped her.

During the interview, she was free and open in discussing with me her experience of living with HIV/AIDS and especially in relation to living with an HIV/AIDS partner. She successfully completed her second, third, fourth and eighth week POS interviews as well had her qualitative interview recorded and reported in Chapter Five. She described her challenges around the areas of disclosure, poverty and its impact on their family, living with uncertainties and fear of death.

4.27 NAMUGERA

Namugera is a 28-year-old married man living with his wife and two young children. His wife is not aware of Namugera's HIV/AIDS. He did not disclose his status to his wife. He is in advanced HIV/AIDS stage IV with co-morbidities. He has KS and opportunistic infections; for example, oral thrush, which affected swallowing food. He is on HAART and cancer drugs. He is very weak-looking, dehydrated, emaciated and has lost his hair. Both his legs were severely affected by KS and he had large discharging wounds which caused a lot of pain and inability to move. He was in bed all the time. Additionally, he had a chronic untreated STI, which had developed into ulcers, so that putting on clothes was a painful experience. He did not travel by public means because of the smell of the wounds.

I recruited and administered the first POS interview at HAU when he was enrolled into the palliative care programme. From the second week, he fell seriously ill and was hospitalised for treatment and management of breathlessness. I did not interview his wife because she was ignorant of Namugera's status. He described his intentional and deliberate actions of indirect disclosure through openly displaying HAART drugs on the table with hopes that his wife will discover that HAART is for HIV/AIDS.

During the interview, he was open and talked freely with me. He shared his experiences of living with HIV/AIDS. He was looking so depressed, anxious and helpless about his state and plans for his family, especially the children. They were living in one small-roomed rented house, which was portioned to accommodate sleeping, sitting and kitchen space; this complicated confidentiality while carrying out interviews. I noticed that Namugera asked his wife to attend to some activity which

technically was intended to send her out of the premises while I carried out the interview. He feared to interact with people because of the HIV/AIDS stigma. I succeeded in following him up for the eight weeks. I carried out qualitative and POS interviews but found it challenging to do so: many times he was hospitalised and was too weak to be interviewed. I rescheduled his interview to later times when he was relatively better.

4.28 SSEMPALA

Ssempala is a 43-year-old male who separated from his wife and left his rural home to live in a semi-urban part of Kampala while doing casual jobs. He now lives alone without a carer, except for one young boy who shares the room but is not always present. His CD4 count is 250 and he has just started taking his HAART. Ssempala had one eye removed in 2008 due to squamous cell carcinoma. His children are with his parents in the rural home; he says that he visits them once in awhile. He says that no-one knows of his HIV/AIDS status and he claimed that he would rather say he suffers from cancer than HIV. He does not want to disclose to anyone for fear of stigma.

I met Ssempala the first time at HAU when he was newly enrolled into the palliative care programme. I administered the first POS interview and scheduled for follow-up at home and at the Hospice. He was still able to walk and so he came for his second and third week POS at HAU. Each time he came to the Hospice, he would specifically ask to see me first. He seemed not to want to share his experience with anyone else.

He opened up and shared his sensitive information after I assured him of confidentiality and anonymity.

During the fourth week, I went to meet with him in his home. He welcomed me and prepared tea. He was happy that I had managed to follow him up, even at home. He was happy to tell me his story of his lived-experience of HIV/AIDS. I enjoyed his hospitality and I felt that I had maintained a good relationship with him. He described his past experience and how he separated from his wife and came to Kampala. He appreciated the efforts HAU were doing to help him to alleviate the pain and distressing symptoms.

He became free with me and, after the interview, he had personal questions which needed a lot of counselling. I referred him to Hospice staff who picked up the discussion.

During the eighth-week POS interview, he did not like the idea that I was now ending my follow-up study. He appreciated efforts from HAU for supporting him and treating him. He was more enthusiastic to advocate palliative care services and promised to refer anyone who has similar symptoms to the Hospice for care.

4.29 WANDIRA

Wandira is a 30-year-old married woman with one child. She is suffering from advanced HIV/AIDS stage IV with KS lungs and opportunistic infections. She was hospitalised due to breathlessness and anaemia. She has lost weight and looked wasted, now weighing about six stones. She was breathless and was on and off oxygen

due to the advanced state. The distressing symptoms and pain were the main concerns, which were being managed jointly by the Hospice and the hospital. Her sister was her main carer at the hospital.

I recruited and administered the first POS interview in the hospital soon after she was enrolled into the new services from the Hospice. I introduced her into the study and she was happy to participate, though with the expectation of better treatment or better management. I clarified my role in the research and referred her to Hospice staff, who explained the role of the joint care she was receiving. During the interview, though she was in distress, she was willing to participate in the study. I made sure that the POS interview did not last long so it did not cause much stress to her. Unfortunately, she did not live long; she succumbed to complications related to advance HIV/AIDS, and died before the third POS interview.

On reflection, I felt I had missed an opportunity to discuss and record her experience of her last days. I wondered whether, if she had received a blood transfusion, she would still be alive. I learnt that timely interventions are needed in the end-of-life care in the area of symptom management, and emotion-psychosocial aspects. The following chapter describes experiences of living with HIV/AIDS among these participants based on an analysis of qualitative interview data.

CHAPTER FIVE

EXPERIENCES OF LIVING WITH ADVANCED HIV/AIDS

5.1 INTRODUCTION

‘From the time I was told, when I got the results, I lost my strength and became weak. I went to the village clinic; they looked for the veins to put in the drip and they couldn’t because they didn’t get the veins. I came back here and I felt something swollen here [pointing at her body], and they told me that I had cancer, but I had HIV/AIDS then. Then I had the thing which was cancer and it has been the most painful. The ‘soldiers’ [CD4 count] are 90. After they told me that they would visit me ... they were giving medicine and food. But then they told us that food is finished, I came back to X ... I got sick for two months. Then they said that I needed to take medication [HAART] again ... I observed that it brought me ulcers/ wounds ... and I was becoming blind; then I gave it up. Since then I have just been taking it and, as I keep observing, let me endure as I observe how I am going to be again.’

(Nankoma, KAF12 interview)

The above quotation by Nankoma, a 39-year-old widow in stage IV (AIDS), demonstrates the main focus of this chapter. Nankoma describes her experience of living with HIV/AIDS and the challenges she has faced. She describes how her health has deteriorated since she was diagnosed with HIV/AIDS. In her interview, she reveals how, when she got the diagnosis of HIV/AIDS, she moved from one health facility to another in search of treatment and help for her distressing symptoms. She reported how she only learnt of her status when she had the advanced disease (CD4

90) and had developed AIDS-related cancers. Though she started taking HAART, she has not always adhered to the treatment. She describes how she takes HAART irregularly because of its side-effects; she is now trying to endure the treatment. Nankoma expressed how she has experienced pain due to the AIDS-related cancer, an experience which is common among PLWA at advanced stages (stage IV). It is also worth taking into consideration the context of her experiences, which is characterised by low socio-economic status. She needed help to get food, which was given by HAU. I observed that those participants who received such food support lived in the most extreme poverty and were unable to sustain their basic needs.

From the stories of their experiences, PLWA who participated in this study revealed characteristic challenges that they encountered. These varied according to many factors, and PLWA differed in their response to them. These are explored in detail in this chapter.

The chapter begins by setting out background information about the experiences of PLWA in the present study. Following a description of participants' general characteristics, their experiences relating to physical palliative care needs are examined, with a particular focus on pain and symptoms and post-HAART experiences. Subsequently, psychosocial and spiritual issues resulting from living with HIV/AIDS are captured and described. The chapter then examines the experiences of caregivers who are mostly family members and what sources of help and support are accessed. The chapter concludes by discussing the key findings in the context of the wider literature.

5.2 SOCIAL CONTEXT

The study largely drew its participants from a bigger population of PLWA living within the environs of Kampala who were seeking palliative care services at HAU. The study was carried out among participants who had multiple challenges. The specific challenges related to participants' stage of HIV/AIDS and ranged from physical, psychosocial to socio-economic.

This section of the chapter therefore aims at describing the context in which the study participants lived. In doing so, it seeks to give a general overview of experiences and views among PLWA and their families. Study participants were affected by several inter-related factors. However, one of the main factors observed among all participants was poverty. Both patients and their family-caregivers/members lived in poverty, which had been aggravated by HIV/AIDS. The situation of study participants must be seen against the wider backdrop of prevailing household poverty in the country. With the country's per capita income GDP of \$300/annum, around 26% (approximately 7 million people) of Uganda's population is estimated to live in chronic poverty, which is seen as an enormous challenge (FAO, 2001).

The following interview extracts in Table 5.1 may give an insight into the impact of poverty on participants involved in this study.

Table 5.1 Experiences of people living with HIV/AIDS

I can also say that we have used all our money in buying food and now we don't have money ... now we don't know what to do ... they have given us admission again here at the hospital because they have said that they have to put her on a drip to receive a blood transfusion. So sometimes I had to walk all alone from village X to the Mulago hospital [distance of 6-8 miles]. Moreover, I would walk to the hospital on a weekly basis without eating anything and stay at the hospital all day waiting to be seen but so weak because I have not eaten and walk back to the house so tired (*Nafuna, KAF21 interview*).

You see we are struggling ... the patient is lying on the mat, no money for medication for the leg, no food, no drink; we are just there (*Kibuuka, KAM25 interview*).

I have my family as well, so adding the responsibilities has not been easy ... It is stressful, especially when the patient needs something or transport to go for treatment and it is not there ... (*Kizza, KAM04 interview*).

They feared a lot ... You know I was vomiting. I had diarrhoea, I was down and I was even going crazy so they said this person [herself] is going to die here ... let us sell her property to take her to hospital ... Now you see I have sold all of them now. I have been selling before for my treatment in 2008 until now I am here. Since I got sick I have been selling my properties ... Now there is nothing; that is why I am suffering now ... now I ask God, I wish ... I don't know ... when I think of my children and I have sold my property and I am still sick and not dying today or tomorrow I feel very bad ... (*Nabukwasi, KAF27 interview*).

I experienced skin problems [KS] that were not disappearing and I used to go Dr. X's clinic in Kampala, but weakness in my body increased and I couldn't walk. He used to help me with some drugs. But now I don't have money ... just borrowing ... and not improving ... feel a lot of pain. I feel like stealing to get money to pay for drugs ... I wish I would die ... I don't know ... (*Lutalo, KAM02 interview*).

I don't like sharing this but, after leaving the job, I had several friends – like my fellow truck drivers and my relatives, who always think about us and when I go out meeting them – like today I went this morning without any cent in my pocket but when you reach there [city] you find that you have been given like Ugsh 10,000 (3 pounds). The following day again you go like that and that is how we have managed to survive (*Ddamba, KAM17 interview*).

Twenty-one participants were bedridden either in their homes or as hospital in-patients. The majority of participants struggled for survival since they had little support. All participants sought treatment with HAART and for their pain and symptoms. From the study findings, it was evident that, as a result of accessing HAART, participants were now living longer than may have been previously expected, but encountered new challenges as a result. The majority of participants identified agencies, networks and social ties (for example the family clan system)

which they accessed for support. Thus, the study took place in the context of care and support provision ranging from family members at home to a number of AIDS agencies. These agencies included: HAU, TASO, radiotherapy, cancer unit-Mulago, HIV/AIDS units in hospitals, JCRC, and Mild-may AIDS centre. Some individuals, especially those from rural areas, migrated to live in Kampala in order to access medical treatment. These migrants faced enormous psychosocial challenges, even if their physical health improved.

All participants had diverse experiences of living with HIV/AIDS, which this study has sought to analyse in order to reveal their needs and consider how best they may be met. Using the main dimensions of palliative care, these experiences have been categorised into three main sub-themes: physical, psychosocial and spiritual dimensions of living with HIV/AIDS. The following sub-sections give details of the three categories.

5.3 LIVING WITH ADVANCED AIDS (STAGES III and IV)

5.3.1 Patients' experiences of pain and symptoms

This section of the chapter describes the patients' experiences of pain and symptoms. It also reports causes, primary symptoms and how these symptoms prompted participants to seek medical treatment. Even with medical treatment and use of disease-modifying therapies (HAART), patients experienced a range of symptoms and associated distress. This issue is explored below.

All participants in this study (*see Appendix XI*) experienced some form of pain. The experience of pain was almost always in the context of other distressing symptoms (such as persistent fatigue) and was common among all participants in an advanced stage of disease, because of the incidence among them of opportunistic infections and HIV-related cancers. These were among some of the most difficult problems facing them. Pain had many causes: sometimes it was related to the distressing symptoms such as pulmonary tuberculosis (PTB), oesophageal candidiasis, herpes simplex/zoster, chest infections and skin problems, commonly observed among PLWA. In some cases, participants experienced extreme and prolonged symptom distress. For example Gwandoya, a married man of 32 years with stage IV HIV/AIDS, describes how he experienced a chronic persistent cough, diarrhoea and fever (*KAM24 interview, Table 5.2*).

I observed that in some cases patients who were in stage IV of the disease were hospitalised for so long that they had bed sores from lying in bed with musculoskeletal

wasting; these sores added to their pain and suffering. Table 5.2 describes the interviews of participants' experiences of pain and distressing symptoms.

Table 5.2 Experiences of pain and distressing symptoms among participants

It was last year [2008] April, I had a fever that doesn't heal. I went to Mulago to check and I was positive ... I also had diarrhoea and back pain. I discovered also that I had TB in April and started taking meds for TB in May and the following month I found out that I also had cancer (*Gwandoya, KAM24 interview*).

I first discovered that I was HIV/AIDS in January last year when I went to test in a nearby clinic called Butemba; after this I went to Hoima. After I tested in Butemba they told me that I am free to go any health facility to get treatment. They tested me again and they started me on Septrin. Diarrhoea and Vomiting together with headache were the major symptoms which I experienced when I decided to go for testing. I also had no appetite; even now I still don't have (*Nabirye, KAF18 interview*).

I was getting fever, chest pain and cough, I wasn't so weak but I had fever and cough and asked the doctor to test this endless fever (*Nabukwasi, KAF27 interview*).

Problems are many; to move to get treatment is a problem. Body also is weak and this part [pointing at his mouth] is painful and I still cough (*Okello, KAM09 interview*).

I started with fever, but I think because we sit on the pick-up when we were going to bring goods from the border of Zaire (Democratic Republic of Congo) to town Y – that is what I think contributed to my fever: sitting on the pick-up while travelling a long journey in the cold. Fever has been disturbing me so much and diarrhoea and vomiting and also coughs on and off (*Mangeni, KAF28 interview*).

Many participants suffered repeated episodes of distress from multiple symptoms. For example, Okello a 40-year-old man in HIV/AIDS stage IV, gives an account of profound multiple distressing symptoms of fatigue and weakness (*KAM09 interview, Table 5.2*).

In some cases, the demands of everyday living worsened experiences of symptoms. For example, Mangeni, a 47-year-old woman in stage III AIDS describes how her symptoms were made worse by travelling on a long journey (*KAF28 interview, Table 5.2*). As previously observed, most of the participants with advanced AIDS (*see Appendix XI*) experienced several symptom-related problems. Some experienced breathlessness and were frequently hospitalised for acute management, including

oxygenation. This was usually a symptom experienced at the end of life. Out of eight participants who died, five experienced breathlessness in their last days.

I will now draw on the data from some participants to examine their perspectives and experiences of breathlessness. For example, Nankoma, a 39-year-old widow reported such an overwhelming experience that she cried while explaining her circumstances. During her interview, Nankoma was quite distressed with difficulties in breathing; she was sweating, emaciated, weak and fatigued (*KAF12 interview, Table 5.3*). Table 5.3 refers to interviews in which participants recounted experiences of breathlessness.

Ddamba is a 45-year-old man and in stage IV (AIDS) with MDR.¹⁵ He was developing complications related to resistant TB, which later developed into breathlessness due to a pleural effusion. His main concern, which was provoking anxiety, was that he would be unable to recover from TB despite treatment (*KAM17 interview, Table 5.1*). In another case, Gwandoya, a 32-year-old man living with HIV/AIDS stage IV, describes how breathlessness can be a disabling and distressful experience. He likened his lungs as having been ‘eaten’ away; he has sleepless nights due to breathlessness (*KAM24 interview, Table 5.3*). In some cases, experiences of distressing symptoms were sometimes the reason that medical attention was sought. For example, Nabukwasi who was a 31-year-old woman, and Nabirye, a 24-year-old woman, reported how serious symptoms prompted them to seek help (*KAF27 interview, Table 5.1; KAF18 interview, Table 5.2*).

¹⁵ Multiple Drug Resistant TB.

Table 5.3 Experiences of breathlessness

The wounds (KS) in the feet are disturbing me. By the time I got off the bed I had some little strength but I was breathless and I said ‘Oh God, why am I breathing so badly with difficulties?’ (*Nankoma, KAF12 interview*)

In the lungs when they examined me they found that I had TB but in the sputum they did not find anything, but the picture showed that I had TB. So when I continued this way and I started swelling in the legs and also feeling the dizziness, they started me on injection and tablets for eight months but then it did not improve: my coughing still persisted and when they took the picture of my chest they still found the disease. They then did a lot of examination. I was referred to many experts even in the hospital. When they saw my picture [*meaning X-ray*] they said that there must be something between my lungs and heart ... like water; and by this time I had the problem of breathing and this is when I was taken to Mulago – to the casualty ward. Then they removed the water. I stayed in Mulago like for a one month, and so that water¹⁶ got over and now they discharged me (*Ddamba, KAM17 interview*).

It was a fever and discomfort in the stomach, feet and my hands ... The lungs, they are ‘eaten’ away and I can’t breathe ... well, even at night I have to wake up and catch my breath (*Gwandoya, KAM24 interview*).

5.3.2 Experiences with HAART

Most of the participants (26) were put on HAART and perceived this treatment to have positive outcomes. Among participants who had symptoms relieved, ten participants were able to resume simple duties (household chores, shopping etc) because the disabling symptoms of AIDS receded. For example, Kakiiza, a 23-year-old single woman in stage III (HIV/AIDS) attributes HAART to getting back to life again and gaining strength to do her chores (*KAF08 interview, Table 5.4*). While some participants perceived positive effects of HAART, many experienced side-effects. Stories of participants revealed contrasting views of HAART. Table 5.4 describes such experiences.

¹⁶ Pleural effusion in the lungs: common with severe chest infections.

I observed that participants' experiences were related to different kinds of drug regimes in HAART. The outcomes of these experiences resulted in some participants being non-compliant. Some participants took HAART irregularly, some endured treatment, and some stopped taking HAART treatment completely. Some tried to combine the problems they experienced with HAART with traditional medicine. There were additional barriers to taking HAART other than primary side-effects that also contributed to non-adherence. These include: lack of food, lack of transport, lack of time-keeping, and lack of access to prescriptions. Table 5.4 depicts experiences of PLWA on HAART. I will now compare participant's experiences of HAART and their outcomes.

Nankoma, a 39-year-old widow, for instance, recalls her initial experience when she began to receive treatment. Referring to her CD4 as 'soldiers' protecting her immunity, she says that she had to begin taking HAART though she suffered the side-effects and had to stop taking it at one point. Nankoma reports an array of symptoms associated with side-effects of HAART. She links her stomach upsets, sight impairments to side-effects which she was trying to tolerate. Nankoma describes how she is now enduring HAART (*KAF12 interview, Table 5.4*). Other participants with similar experiences included Lutalo a 38-year-old man. Lutalo experienced chronic constipation as a result of HAART. At his interview, Lutalo had stopped HAART but began again shortly after he enrolled on palliative care. However, he now has concerns on taking food because he fears the return of the constipation (*KAM02 interview, Table 5.4*).

Table 5.4: Experiences on HAART

That is when they started me on ARVs and until now that is what I am taking. And that is what I will continue taking until I die. When I started taking ARVs I discovered that my strength was returning so I decided I am going to continue on them. It was the best medicine for HIV. I feel much better, since I got ARVs my strength returned and I can do my work, even the housework I can manage to do it alone at home (*Kakiiza, KAF08 interview*).

The ‘soldiers’ were then 115, they decided to give me drugs (HAART) for two months. I got sick for two months and I was bedridden. They realised that my ‘soldiers’ had reduced and then they said that I needed to take the medication again for one week. I observed that it brought me ulcers and lack of appetite and I was becoming blind; then I gave it up. Since then I have been just taking it, and as I keep observing, let me endure as I observe how I am going to be again (*Nankoma, KAF12 interview*).

You see I started HAART like a month ago but have been off for three months. My main problem is pain because the main thing which worries me is going to the toilet: I am constipated ... I fear to eat or can’t drink because it will be war for me to remove it. After going to the doctor X for chemo, I could not walk but after injection I was okay. The ARVs had not made any change. I get ARVs from IDI [Infectious Disease Institute]. My brother helps me in transport, I am with him most of the time ... (*Lutalo KAM02 interview*).

I stopped for some time because I didn’t have food to eat. I stopped like for a month. The reason why I stopped taking drugs is because, when I take it with empty stomach, I feel like vomiting (*Nafuna, KAF21 interview*).

I have ever gone to a witchdoctor staying in the sides of Nakasero (Kampala), and it was my daughters who used to take me there and the witchdoctor would give us a pounded form of herbal medicine ... with instruction to boil them and give me to drink plenty of it ... (*Mangeni, KAF 28 interview*).

Nafuna, an 18-year-old single lady, in her account clearly demonstrates how her HAART adherence is affected by the side-effects. Her experience is confounded by poverty. Nafuna says that she cannot continue with treatment (HAART) because she lacks food and feels nausea whenever she takes the medication. In another case, Mangeni, a 47-year-old woman, claims to have mixed her treatment with herbal medicine to reduce distressing symptoms.

As seen from 26 participants’ accounts, it is evident that disease-modifying therapies or use of HAART (*see Appendix X*) had positive impacts on patients with advanced HIV/AIDS but also some difficult side-effects. Negative consequences associated with HAART therapy experienced by PLWA affected their compliance with treatment.

Summary

Study participants were living in poverty (*see Appendix XIII*); they struggled to manage symptoms on their own and experienced difficulties with their treatment. For this reason, some symptoms persisted and were poorly managed. In most cases, patients sought care in a late stage of disease when complications and opportunistic infections were in evidence. Findings show that the burdens of HIV/AIDS-related symptoms differed from one individual to another. This depends on many factors like sex, age of participant, poverty, therapeutic interventions and other available support. Participants' most frequent symptoms included: increased feelings of persistent general weakness and fatigue, body pains or painful joints, severe headache, diarrhoea, anorexia, cough, night fever and opportunistic infections like PTB. Similar observations were observed with measurements of palliative care outcomes. Using the APCA African POS tool reported frequent symptoms distress in the initial weeks of enrolment into the programme: details of it are described in Chapter Six.

5.3.3 Psychosocial issues

This section of the chapter begins with narrative accounts of experiences of people living with HIV/AIDS (PLWA) as well as their caregivers. The challenges and problems related to psychosocial issues are explored from the perspective of patients and informal caregivers. Although they are not easily divided, patients' and caregivers' perspectives are presented separately.

5.3.3.1 Psychosocial issues: patient's perspective

PLWA experienced diverse psychosocial issues, particularly those living with HIV/AIDS who were in a bedridden state. Illness and its disruptions to normal daily living brought enormous psychosocial challenges, which can be divided into two main themes:

1. Disclosure
2. HIV/AIDS stigma
 - i) Lack of support
 - ii) Loneliness

These themes are examined below.

5.3.3.1.1 Disclosure

Fifteen participants in this study revealed that disclosure of their HIV/AIDS was a particularly sensitive issue. Participants expressed difficulties associated with disclosure of HIV/AIDS to their family members and friends. This is because of fear associated with the HIV/AIDS stigma, the risk of losing the support of friends and family and, in many cases, the fear of blame or of losing one's livelihood or means of support. An examination of participants' views and experience about disclosure clearly reveals that participants weigh up a number of issues before disclosing. Where disclosure was perceived to be leverage for support, participants sought to use several strategies to disclose. To illustrate this, I will use various participants' experiences of disclosures and identify the underlying factors influencing each strategy. Strategies

commonly used were: indirect approaches, implied disclosure, disclosure to trusted confidants, and in some cases non-disclosure.

Where participants dreaded to disclose their HIV/AIDS for fear of negative consequences, an indirect approach was often adopted or preferred. This was a common strategy among parents when they attempted to disclose to their children. Most parents expressed difficulties in the way in which disclosure to children should be handled and this was among the most challenging of situations.

For example, Ssematimba, a 44-year-old man introduced above, reported the difficulties he had in handling children's curiosity. His wife also reported how she avoided the children's questions and referred to Ssematimba as 'doing poorly'. Similarly, Agaba, a 40-year-old woman in stage IV (AIDS), did not openly break the news to her daughter. Instead she asked her daughter to accompany her to hospital when she was ill. While in hospital she left her daughter to be told by the health worker.

Disclosure to other family members was also experienced as challenging and complex. For example, the story of Lutalo, a 38-year-old man, who reported how he had to move to stay with his brother for fear of disclosing to his family members. His story is captured in detail in Chapter Four. In the case of Ssematimba, a 44-year-old man, an intermediary family member was asked to take the news to his family, because he found it hard and challenging to do it himself. He worked out a plan to request his brother to accompany him to hospital. While in hospital they both went to have voluntary counselling and testing (VCT) for HIV/AIDS. In the process, the brother learnt that Ssematimba had HIV/AIDS. The brother then acted as an

intermediary to communicate to the rest of the family members. Table 5.5 depicts the experiences of disclosure among PLWA.

Some participants deliberately chose to avoid disclosing without giving a specific reason. Meanwhile, other participants chose to use overlapping terms which in a sort of way avoided use of direct simple terms to express their health status. Participants instead preferred to trickle information slowly so as to imply they are not healthy. I have referred to this strategy as implied disclosure. In using this strategy, participants were careful in their choice of words when explaining their status while remaining silent in use of such terms as 'I have HIV/AIDS'. I noticed that use of silence was a coping strategy in order to avoid anticipated consequences. In doing so, participants succeeded in keeping information to themselves. For example, words such as 'they found me ill', 'I am not OK', 'weird disease making my legs swell', 'the leg has cancer' etc. In some cases, participants assumed that family members would observe physical symptoms (AIDS) and connect these to the reality of their diagnosis.

Among some other participants, the HIV/AIDS stigma influenced disclosure. For instance, Amandua a 20-year-old high school student describes not only the fear of rejection due to the AIDS stigma but also the fact that his friends would gossip about him if he discloses. Amandua cautioned me not to mention to anyone about his status when I visited him. He had told his colleagues that he has cancer rather than HIV/AIDS.

Amandua's experience was also voiced by Nafuna, an 18-year-old girl. While citing fear of gossip, stigma and questions around morality from family members, Nafuna decided to keep the information from some of her family members who were not

showing support to her. However, she describes how, when she relocated to Kampala, she found a loving and caring sister-in-law who did not discriminate against her and, as a result, she felt able to disclose freely. Similarly, Nafuna's experience was also voiced by Kakiiza, a 23-year-old woman in stage III (AIDS). In my view, disclosure was a highly debatable issue and, where forecasted support was anticipated, disclosure was done with ease to ensure access to support. In contrast, where participants felt that there was no forthcoming support or that disclosure would damage access to support, they kept their diagnosis to themselves. Table 5.6 describes experiences of disclosure by the participants.

Table 5.5 Disclosure experiences among PLWA

When I was ill, she came and I told her that let's go together [to hospital], so they told her when I was also around and she understood it. They also gave me the medicine [HAART] when she was there (*Agaba, KAF05 interview*).

I told my brother that my body is ill. So I first convinced him to go to hospital with me. We then actually tested with my brother and for him he was negative and he waited for me to get the results and later on I started on treatment ... I told my family members that the last time they took off blood from me they found me ill and I need transport to go for treatment (*Ssematimba, KAM01 interview*).

They ask me what is wrong with our father ... what is our father suffering from? ... but I tell them that he is doing poorly (*Ssematimba's wife, KAM01 interview*).

She would have spread the news to the village and not kept it to herself. I think she would have even told her daughters and I don't go along well with her daughters because whatever I do she still tell her daughters and would have laughed at me and among the daughters no one would help me. Where I used to stay at my auntie's place, I didn't tell anyone of my status. The only person who knew was my brother. Where I live now at my brother's house they know because they love and no one discriminate me, they treat me like any other family member. But when I was at my auntie's place they used to discriminate against me on the basis of those cancer swelling they had thinking that it would be transmitted to them (*Nafuna, KAF21 interview*).

Almost all the family members know ... You see when I got sick they see your situation changing each day; they suspected that I have HIV. I told my children that they were treating cancer. I told my sister Jane they are treating me for cancer ... But my brother knows from Nakasero. Since we were raised together I told him I am not OK (*Nabukwasi, KAF27 interview*).

At first, I experienced some uncomfortable expressions [stigma language], but by the help of counsellors ... I did not disclose to anyone in school; they just knew that I was suffering from a weird

disease which had made my feet swollen and was seeking medical attention. My colleagues would talk about me. Even here at the workshop they see me like anybody else, they look at the leg and I tell them that it is cancer (*Amandua, KAM11 interview*).

I told my brother – the one I live with – that I have been tested and I have HIV. My brother told me not to worry. My family here in Kampala knows that I am HIV positive but the ones in the village don't know. All my siblings in Kampala know that I am HIV positive. He doesn't give me much help but the help I get from him is that he sustains me from his home and he feeds me but he doesn't have much money (*Kakiiza, KAF08 interview*).

As noted above, where patients perceived that they received spiritual support, counselling and guidance from their family members, friends or other supporters, the matter of disclosure was more easily pursued. Typically, patients told their relative(s) for material support, the pastor (for spiritual support), or the CHW (for community support). In such instances, participants were seen to benefit from psychosocial support activities such as frequent visits, access to medical support, counselling, or creating links with other support groups. For example, among the participants in this category were Adongo, a 40-year-old woman, and Amandua, a 20-year-old boy. I have described their experiences in detail in Chapter Four. These examples show how anticipated support was leverage for disclosure. Where participants anticipated support, they easily opened up their status in order to access some form of support.

Some participants, especially those who had partners (wife or husband), attributed disclosure to accessing support from their partners. However, where participants anticipated negative consequences, they chose not to disclose. Among them were participants who expressed fears related to their partner leaving them, being blamed, and/or uncertainties about whether support would continue to be forthcoming from the partner. Individuals who shared this experience expressed concerns around aspects of morality by their partners and blame for bringing the deadly disease into the family. The stories of Kizza, a 28-year-old married man, Ssempala, a 43-year-old married

man, Gwandoya, a 32-year-old married man, and Nabirye, a 24-year-old, demonstrate the challenges which related to disclosure within marital relationships. Ssempala's story in Table 5.6 for instance connected his story with possible stigmatisation in the community. He expressed his reservation on disclosure.

Table 5.6 Disclosure experiences among PLWA

<p>I have not yet told my wife: I fear that she would run away and leave me alone (<i>Kizza, KAM04 interview</i>).</p> <p>No one knows, not even here at home ... In the hospital, we talk as patients, but for my friends no one knows, Someone don't understand what it is secret; if you tell someone, by two days you find someone says that one you see is sick. That is why I keep my promise of keeping it to myself (<i>Ssempala, KAM26 interview</i>).</p> <p>He didn't tell me, now you would know what is going on because we have seen some people with HIV/AIDS. His mother and one relative told me you are seeing the situation: go and check yourself [test] and see if you are sick; you can begin to take the medication because you have seen how the things are. Then I went to the Hospital in X area, you know the hospital ... That is where I went ... They asked me what has pushed me to come here, I told them that my husband is bedridden and therefore I want to know my status so that I can start taking medication (<i>Gwandoya's wife, KAM24 interview</i>).</p>

In this sub-section, I have discussed the psychosocial issues surrounding experience of disclosure and non-disclosure as narrated by PLWA who participated in this study. Drawing lessons from various interviews, it became clear that disclosure is not an easy matter. Participants debated how to manage information relating to their status. I learnt from participants' narratives that disclosure takes different angles depending on the perceived consequences. Some participants who felt that disclosure would be detrimental or would stigmatise them kept it to themselves or adopted alternative ways/approaches to disclosure. The majority of participants preferred certain ways of disclosure that would limit provision of the information to trusted confidants or to an individual who would give some support. Disclosure in some instances was support-

motivated. In doing so, some participants felt that the trusted confidants would slowly play an intermediary role to convey the message to the rest of the family members. As seen in participants' interviews, it was perceived that the information regarding the HIV/AIDS status would be managed within the 'inside' circle of the family. This was meant to avoid stigmatisation or gossip in a communal setting of participants.

5.3.3.1.2 HIV/AIDS and stigma

Findings of this study suggest that the HIV/AIDS stigma amongst PLWA in Uganda is still profound. With a variety of impacts, participants associated their concerns surrounding disclosure, support and job security, discrimination or losing friends with the HIV/AIDS stigma. In most cases, participants felt that living with the HIV/AIDS stigma is distressing because of its negative consequences.

AIDS symptoms such as fungating wounds (KS), blotched skin (KS skin), wasting and TB were perceived to be stigmatising in the community as these symptoms are recognised to be closely related to AIDS. For example, Amandua, a 20-year-old man, reported how he connects his physical changes due to advancing HIV/AIDS to his inability to interact with others while playing games together with other colleagues. He notices changes in social interaction which he attributes to the way he looks. He perceives a changing physical self image due to AIDS to be the cause of not being able to mix well with others. Some participants reported tendencies to avoid social places. For example, Nabukwasi, a 31-year-old woman, reported that she had a 'decaying leg' the smell of which affected her social interactions with people. Her boss threatened to lay her off from work because of this. This finding illuminates the potential for discrimination at the workplace against PLWA.

Nabukwasi's experiences were reflected in other cases. For instance, Okello's wife describes how, when her husband got HIV/AIDS, they were both abandoned. They likened their life to being exiled or banished by their own community. Responding to the interview question 'how is your experience of living with HIV/AIDS?', Okello's wife gives a vivid description of how she has suffered stigmatisation. She says her relationship with others is no longer the same since the advent of HIV/AIDS in her family. With Okello, it is clear as he narrates his story that life is no longer the same. He describes how stigma can be a barrier to accessing support. Similarly, Kakiiza, who is a 23-year-old woman, reveals further experiences of manifestation of the AIDS stigma in a society. To her, the family left her without any support while isolating her from others due to the HIV/AIDS stigma. These discriminative actions were evident when the family decided to treat her differently by giving her different utensils and a different room to live in. Table 5.7 gives descriptions of experiences of the HIV/AIDS stigma among PLWA.

Table 5.7 HIV/AIDS Stigma experiences among PLWA

Now I lost my normal shape and I did not want people to see me ... Even people at home started to isolate me ... you find they say 'don't use our basin, don't use our cup ... use your own cup ... get your own plate' ... those things ... it is the same ... even here in Kampala I have my own cup, my own plate and my own basin ... Now I am used to ... I don't feel good but I have nothing to do ... I remember a few, the leg got swollen and I thought it was a weird disease ... and then it was exfoliating and 'rotting'. I used to go the clinic and I was treated and they told me to go to Mulago and the legs were 'rotting' and I couldn't even go around people ... I used to work in an hotel [as a waiter], and she [the boss] feared that I would stick to her in my final stages of my disease, so she kicked me out of the hotel and left. She use to like me before ... I would peel the potatoes and any other job ... but she doesn't want me to continue working there ... (*Nabukwasi, KAF27 interview*).

When people at home discovered Okello had HIV/AIDS and cancer, they left us and abandoned us, so we learnt to be on our own ... Now money is over and we are now walking on foot in the Kampala Street, hoping to get someone to help us. If we get a 'good Samaritan' we will thank God (*Okello's wife, KAF09 interview*).

They were giving me a special cup and utensils in my own room. I would be shaking but people leave me alone and people would not help me (*Kakiiza, KAF08 interview*).

You see my appearance is not good ... Inside me I have a feeling that perhaps HIV/AIDS is the cause of not mingling well with others in that centre I was in with other colleagues (*Amandua, KAM11 interview*).

At one point I had a sort of isolation but now no more because many people have been affected or infected ... I am ill and I had some self-pity. I had become so thin because TB had made me look so bad and I was in the house with no strength. But I did not fear that people would look at me with a different perception but I didn't have strength ... Though it can happen, when the person looks at you too long you get that feeling ... (*Gwandoya, KAM24 interview*).

I am living like other people; I have gotten used to ... I have also seen many people who are like me and this has strengthened me and I no longer fear ... There is a woman who stays close to where I live and has the same illness, she directed me to Mild-may ... (*Agaba, KAF05 interview*).

In contrast, some participants held different opinions and experiences. They viewed the HIV/AIDS stigma as having decreased. They argued that every family is either affected or infected in one way or another and that, therefore, stigma was not such an issue. For example, Gwandoya, a 32-year-old man, describes how he no longer experiences discrimination although he is not sure about how others perceive him (*KAM 24 interview, Table 5.7*). Gwandoya claims that he observes how other PLWA cope with AIDS in their daily living and this helps him to live positively.

Gwandoya's experiences were echoed in other cases. For instance, Agaba, 40-year-old woman, says 'I am like other people', referring to other fellow Ugandans who are either affected or infected in one way or another by HIV/AIDS. To Agaba, either a friend or relative or someone in the community is affected, therefore making every family household affected in many ways. In her account, she reiterates the fact that she has seen others like her and she draws strength and lessons. In conclusion, this part demonstrates how HIV/AIDS features as a stigmatising illness in the experiences of participants, with extensive social consequences. It is clear from the data that some participants, especially family members, experienced transferred AIDS stigma.

However, for some participants, their experience of the HIV/AIDS stigma was different. Among this group, they did not perceive much stigma as they perceived that the impact of HIV/AIDS was so widespread in the community.

i) Lack of support

Several participants echoed experiences of lack of support due to several reasons, but mainly stigma and data from the study suggest that there were close links between lack of support, isolation and AIDS stigma. A typical case is Okello, a 40-year-old man in stage IV, which has been described before (*KAM09 interview, Table 5.8*).

A similar observation was made with a number of participants, like Kizza, a 28-year-old man, and Ssempala, a 43-year-old man. Ssempala, for example, in his advanced AIDS with fungating KS on his hands, chose to not to disclose to his family in a rural home and went to live with his sister in Kampala in order to access treatment. Like several participants who left their rural home in search of treatment in urban areas (Kampala), they all had common characteristics: migration was motivated by the clan system as a fallback position for accessing support. The role of the clan system in an African setting seemed to play a significant role in rural-urban migration. Patients identified distant relatives who would be able to provide support such as access to treatment and other HIV/AIDS services. Common rural-urban migration was evident among PLWA who experienced lack of support to access AIDS services in rural areas which were almost non-existent. This finding illustrates prevalent medical disparities and inequalities in several parts of Uganda (*Nankoma, KAF12 interview; Kizza, KAM04 interview; Okello, KAM09 interview; Mangeni, KAF28 interview; Musoke,*

KAM29 interview; Nabirye, KAF18 interview) (see Appendices XII, XIII and Table 5.8).

In most villages, the HIV/AIDS scourge affected family members in various ways. HIV/AIDS has threatened to almost wipe out some families, leaving no support for any remaining survivors. Nabukwasi recounts her plight of how she has been left alone (though now suffers from AIDS), still surviving with her elder brother after HIV/AIDS plagued their family members.

Table 5.8 Experiences of lack of support among PLWA

Now ... here where we live the person does not give us money, only accommodation; we sleep in the sitting room, we get little money from my sister [who is in Soroti, 200 miles away]. In all problems. All ... we expect to get from Judith [the sister]. I see that she helps me with everything; she is the one who financially supports us even to come to Kampala. But where we are in Luzira [Kampala suburbs], there are a lot of problems ... we don't know why he doesn't help us so we call Judith, we have her number, we just walk to public calling booth but now we don't have money to call her. The person accommodating us is also unable. He cannot give us food or transport, he also has many problems, and he is also struggling with many needs so we gamble¹⁷ our way to hospital (*Okello, KAM09 interview*).

They are all dead, except my elder brother who is supporting me, the one you rang in Nakasero ... I get medicine but now you found me lacking soap and paraffin [fuel for kerosene lamp]. My brother gives me transport but I am uncomfortable to ask him for other things so I have to fetch around/borrow ... I am worried about those burdens; the dad is dead and I am ill ... as you know girls or young girls ... she left school. Oh my children: one is here, only God knows (*Nabukwasi, KAF27 interview*).

The interaction of stigma and lack of support meant that participants lived with barely adequate facilities and few basic necessities. I will examine experiences of participants who lived in such situations. For example, in the study, an encounter with impoverished families due to HIV/AIDS leaves no doubt that HIV/AIDS not only incapacitates the patient but also poses a huge household burden. The AIDS impact is felt at household level in different ways. A common experience of suffering among

¹⁷ Risk walking a long distance in search of treatment and taking a chance, hoping to reach hospital with or without transport or food: the harsh aspect of living with HIV/AIDS without support.

families with an AIDS patient was change or swapping of roles, for instance where the patient was the breadwinner. Where a partner or family could not offer enough support, the patient experienced difficulties related to access to treatment and management of AIDS. This experience sometimes led the person to a state of helplessness. Where a patient felt helpless and unable to access treatment, alternative treatments were sometimes sought. Use of traditional herbs and healers were common among some PLWA. Use of alternative therapies was observed among Kakiiza, a 23-year-old woman, Lutalo, a 38-year-old man, Mangeni, a 47-year-old woman, Adongo, a 56-year-old widow, and Gwandoya, a 32-year-old married man.

In conclusion, this part reflects gender inequalities as it reveal that most participants discussed here were women. Women as opposed to men seemed to have faced disproportionate challenges and lacked support.

ii) Loneliness

Findings of this study suggest that participants who were left with little or no support suffered loneliness at one point or another. Some participants were left on their own to struggle and survive (*see Appendix XII*). Experiences of living in loneliness to some extent were also attributed to the HIV/AIDS stigma. They were isolated from the community because of HIV/AIDS for many reasons. One of the reasons is stigma, but also family reasons were cited. Their accounts reveal what might be called 'island experiences' such as separation or divorce. For example, Ssempala, a 43-year old man, described how his wife left him after he got HIV/AIDS in 2005. Ssempala has since then relocated to live in Kampala. He recalls his past relationship and desires company (*see Table 5.9*). Similarly, Nabukwasi experienced some form of loneliness

in her advanced stage of HIV/AIDS. She describes how she was left alone to live and struggle with day-to-day demands and growing needs. Among other participants who suffered loneliness and lack of support towards their last days were Mangeni, a 47-year-old woman, Ssalongo, a 33-year-old man, Mugagga, a 31-year-old man, and Nabulungi, a 47-year-old woman.

Table 5.9 Experiences of loneliness amongst PLWA

<p>I used to have a wife but, in 2005, she was staying with me then when she started tampering herself with other men [unfaithfulness] and then she disappeared. Me, I say if she has done what she wants, I will leave her. I started doing my work; at that time when I was trying to get someone my eyes started getting ill and now I stopped everything. Can I get someone? You see I am lonely and need to keep myself out of loneliness (<i>Ssempala, KAM26 interview</i>).</p>
<p>I have had many challenges in my life since I got HIV... sometimes I don't have money, sometimes I don't have care when I am in the hospital ... I find myself alone; no one helps me when I want something ... I am left by myself [no relative or caregiver to assist]. When you want to call someone, he or she is in his own business; they don't mind whether you are there or not (<i>Nabukwasi, KAF27 interview</i>).</p>

As seen in the above accounts, the findings suggest that HIV/AIDS may cause turbulent relationships, which lead to loneliness due to lack of support or abandonment.

5.3.4 Spiritual dimension

5.3.4.1 *Role of spiritual care*

Five participants in this study reported that spiritual issues were important aspects of their lives (*see Appendix XII*). This group of participants connected their situation to God and in this way found meaning in life. This experience helped them to gain hope and live positively. In this study, spiritual and religious concerns were found to be important for some participants, especially when no one could give answers about their state or when they experienced existential and spiritual distress. Some participants who attached value to spiritual matters embraced religious belief systems and prayer as a means to cope with hopelessness. Participants who linked spiritual matters to their lives included: Kibuuka, a 43-year-old man, Adongo, a 40-year-old woman, Nabukwasi, a 31-year-old woman, Amandua, a 20-year old orphan, and Gwandoya, a 32-year-old man. Adongo's daughter describes how, when her mother realised that she had HIV/AIDS, she proposed to meet with a spiritual leader for prayers and spiritual care. Adongo's daughter's narrative revealed that the church played an important role in the spiritual care of her mother through instilling hope, encouragement and spiritual counselling. Adongo's own account shows that she regarded spiritual leaders as trusted confidants in whom she could confide and disclose confidential information. Adongo opted to confide in a pastor for purposes of spiritual care before even the family knew that she had HIV/AIDS.

Table 5.10 Spiritual experiences of PLWA

After testing, she didn't tell us; she went to church, and so from the church she collapsed. We picked her up from the church that day and we took her to Mulago Hospital. Then they told us to go to the cancer clinic. That's when we realised (*Adongo's daughter, KAF05 interview*).

You see doctor [referring to the researcher], I don't have a girl friend ... Is there another way? You mean someone can acquire from the wind? Anyway I am strong ... What makes me strong is God alone. Yes, after checking me that I have HIV, I handed everything to God. I have not committed any crime [referring to immorality]; it is God to judge. I know God will heal me; when you pray loud to God, can't he listen and heal you? (*Amandua, KAM11 interview*).

Now I went for a certain pastor to pray for me ... I reached there ... they asked for my paper ... radiotherapy, chemotherapy and hospice paper, so that they could pray for me ... they confused me ... there in the church they wanted the paper confirming that the eye has cancer. At that time I say 'if God wishes I will get well' ... At that time I went to hospital to remove the eye ... because at that moment the eye was hurting me so much. In hospital they said they would like to take this small part to hospital [biopsy] ... then after that they said 'let us remove the eye' ... (*Ssempala, KAM26 interview*).

God is there for me ... I have been praying ... I even got saved ... I told God 'you know everything ... you are the one who created me ... you know why it happened' [while raising her hands up to God]. Friends ... have been there for me ... but they also get tired ... they have their own business. Just support ... in terms of financially – they give me some money; one today gives me something then tomorrow another one brings something [money]. Relatives ... are there also ... we are not rich but just there. Average ... medium family and secondly I don't have parents. My father died, my mother died so you find that you are in your own (*Nabukwasi, KAF27 interview*).

The other support, like money to buy drugs for cancer because they are expensive; we receive much support from the church/church members. Like, for instance, there are some medications that I cannot get from Mulago Hospital so I get it in Wandegaya and I buy for Ugsh.12,000 (4 pounds) (*Gwandoya, KAM24 interview*).

Born of a mother with HIV/AIDS, Amandua, a 20-year-old young man, who was left an orphan when he was only two years, does not understand why he is suffering. In his story, however, he says he has surrendered all his 'mysterious health status' to the Supreme Being. This appears to be because he does not know and understand how he contracted HIV/AIDS (*see Table 5.10*).

Other participants had a different story. On the one hand, the experiences of Ssempala, a 43-year-old man who is separated from his family, reveal that not all spiritual leaders can understand emotional and spiritual needs of terminally-ill patients. On the

other hand, Nabukwasi describes her coping strategies around spirituality. In her narrative she seems to be able to find meaning for life through a sense of reconciliation with her creator. She reports how she draws strength from believing that God knows why things happen in the manner in which it happens and describes how prayers have helped her to cope with HIV/AIDS. Similarly, Gwandoya, a 32-year-old man, reported how religious organisations or churches have provided him with emotional, spiritual, and financial/materialistic support. On reflection, medical facilities, including drugs for cancer and distressing symptoms, seem to be unaffordable, and charitable organisations like churches are assisting poor patients through donations. In addition, there is usually an unspoken fear of death related to terminal illness, leaving many to seek emotional and psychological care in churches.

In the interviews of the five participants referred to above, the spiritual aspect of their lives emerged as a means of supporting their coping strategies which enabled them to live with HIV/AIDS.

5.4 CAREGIVING EXPERIENCES

5.4.1 Introduction

Findings of this study suggest that the majority of caregivers helped their relatives meet the needs of their patient(s) under challenging conditions. In most cases, family members helped their relatives by reminding them to take HAART (adherence), offering personal care and enabling continuity of care once their relative was discharged from hospital. Although family caregivers helped their relatives in several

ways, they did so with little or no support, and this had severe impacts upon them. Some caregivers were also ill, often with HIV/AIDS themselves. The following describes findings of qualitative data on the psychosocial impacts of caregiving.

5.4.2 Psychosocial issues: caregiver's perspectives

- Lack of support and resources
- Fear of contagion
- Burden (emotional and physical)
- Support by and for HIV-positive partner
- Anxiety during the last days of life

5.4.2.1 Lack of support and resources

In the interviews, caregivers reported that they found it difficult to access help and were trying to provide care in poor conditions, which was a great impediment to the quality of care they could provide. As a result, caregivers or family members were emotionally drained and exhausted. Among the participants in this category include family members of Kizza, a 28-year old man, Amandua, a 20-year-old boy, Okello, a 40-year-old man, Nafuna, a 18-year-old woman, Kakiiza, a 23-year-old woman, Gwandoya, a 32-year-old man, and Kibuuka, a 43-year old man.

For example, Kizza left his family in his rural home to stay with one of his sisters in Kampala in order to access medical treatment. Whilst this was important for Kizza, his sister's story reveals the challenges this posed for her. She admits not only being

unable to meet Kizza's expectations of support adequately, but also to feeling guilty. As a housewife, she says that they depend on her husband's earnings (<£2/day) to meet all costs: housing, meals, transport and other bills. Her story shows how she is struggling to support Kizza by not only providing accommodation to him but also in supporting him as he seeks medical intervention. She describes the inconvenience of living with Kizza in one small bed-roomed house with children (*KAM04 interview, Table 5.6*).

The experience of Kizza's sister was also voiced in other cases. For example, Amandua's guardian says how he feels unable to meet Amandua's needs due to his own lack of support: he is struggling to meet his family's needs while offering help to Amandua, whom he adopted whilst he was a young orphan. As a Good Samaritan, Amandua's guardian offered to take responsibility when his single mother died of HIV/AIDS when Amandua was aged two years old. Amandua's guardian is now frustrated due to what he perceives are Amandua's unrealistic expectations. He reports that Amandua does not appreciate him. Describing his experience, he says that he has no other sources of income to support Amandua, but was grateful to HAU for its support through the supply of a basic package kit.¹⁸

In a similar account, Nafuna's sister-in-law in her story reports also difficulties related to caregiving, involving frustrations related to care and financial difficulties. Nafuna's sister-in-law is worried with every new hospital admission because of its resource implications. Nafuna, an 18-year-old woman in stage IV, is acutely ill and is anaemic and weak. From the story, it shows how frequent hospitalisation is an additional

¹⁸ This is basic support with food ration weekly and waiving of treatment offered to poor participants enrolled at HAU.

financial stress to the family and participants without support (*KAF21 interview, Table 5.11*).

Table 5.11 Experiences among caregivers for PLWA

I can also say that we have used all our money in buying food and now don't have money ... now they have given us an admission again here at the hospital because they have said that they have to put her on a drip to receive a blood transfusion (*Nafuna's sister-in-law, KAF21 interview*).

On several occasions, the patient wants good food; when you give him what you have, he refuses and does not understand the situation. Yet there is no money ... you know, like now I am not working ... I sometimes try and slaughter chicken for him ... I have some free-range poultry (*Amandua's guardian, KAM11 interview*).

The situation is not that good, food is lacking sometimes, transport is also hard to get; sometimes you may want to go and pick the drugs but the money is not there (*Kakiiza's sister, KAF08 interview*).

You see, we are struggling for help when the patient is lying on the mat; no money for medication for the leg, no food, no drink – we are just there ... (*Kibuuka's wife, KAM25 interview*).

I have sacrificed a lot but the support is limited and the leg is not improving. I am so keen on pressing the leg to squeeze the pus out of the leg (KS) but no improvement. I do this every day and I have to put on medication every day, but it runs out fast so I don't see the effect of what I am doing (*Kibuuka, KAM25 interview*).

It is hard, very hard. I get tired with a little baby who is four months and we are in hospital all the time; we sleep here ... (*Okello's wife, KAF09 interview*).

In addition, when I visited Kibuuka, who was a 43-year-old man, his wife told me how they have found themselves in a helpless state, with no food, nor money to buy a drink (*KAM25 interview*). While the majority of caregivers said that the most difficult thing was the provision of care in a resource-constrained setting, some had different experiences. For example, Okello's wife reported that managing a fungating wound at home (due to KS) and access to medical treatment was the greatest challenge (*KAF09 interview, Table 5.11*). With a lack of support, Okello's wife, who was the mother of a four-month-old baby, struggled to take care of her husband. She recounts her

experiences of having to stay in the hospital to take care of Okello. She undertook a lot of responsibilities because no one was ready to help her (*KAF09 interview, Table 5.11*).

As seen in the accounts above, caregiving in the midst of extreme poverty is clearly a huge challenge. Outstanding challenges related to lack of support were evident in caregivers' stories. Other challenging areas include uncertainty about roles and expectations and inaccessible medical treatment.

5.4.2.2 Fear of contracting HIV/AIDS

Fear of contagion was expressed by four caregivers who felt they were potentially at risk of contracting HIV/AIDS. They attributed this to lack of protective devices while taking care of their relative. For example, the wives of Kibuuka, a 43-year-old man and Gwandoya, a 32-year-old man, and the caregivers of Nabiryea, a 24-year old woman and Mangeni, a 47-year-old woman, faced dilemmas about how to handle occupational exposure to HIV/AIDS when giving care. Caregivers usually had to provide personal care such as dressing or wound cleaning and handling any discharges/fluids with their naked hands. Some perceived HIV/AIDS as 'any other disease', though they remained in fear of it. Some had unanswered questions in their minds about their status which worried them. The majority of caregivers wished that health care workers would supply them with gloves, cotton wool, sanitary materials and some infection-control knowledge. For example, Mangeni's sister-in-law described many problems related to inadequate sanitary facilities and feared that she might have contracted HIV/AIDS due to using her bare hands for personal care (*see*

Table 5.12). Her main concerns were lack or unavailability of safe care facilities, which included lack of bandages, pads or any cotton wool. Nabirye's sister describes how she supports Nabirye's day-to-day needs but raises concern about lack of gloves (*KAF18 interview, Table 5.12*). In addition, Gwandoya's wife narrates experiences where she lived in fear which propelled her to go to hospital and test for HIV after a friend suggested. In the narrative, it depicts a context of uncertainty which made Gwandoya's wife live in fear of contagion (*KAF24 interview, Table 5.12*).

Table 5.12 Experiences of fear of contagion among caregivers

I help in many ways, including the transport to come to hospital. I don't have real difficulties on my part. The only challenge is handling her refusing to eat because when she does not eat I feel anxious ... I don't wear gloves ... (*Nabirye's sister, KAF18 interview*).

You see I am like this ... she has diarrhoea ... sometimes her clothes are soaking wet and I need to clean, I need gloves. I thought you have them so that you can help me. I even don't know whether I have contracted, you see I don't know my status (*Mangeni's sister-in-law, KAF28 interview*).

Because even my father got HIV/AIDS and I cared for him and so I know ... You see, when I knew that you are coming to see Kibuuka, I said to myself that I will plead for gloves and medication [morphine etc]. Touching the wound with bare hands is difficult and scary ... because I wash him and touch everything ... (*Kibuuka's wife, KAF25 interview*).

A friend told me you see ... we have seen some people with HIV/AIDS ... Seeing the situation, go check yourself [test for HIV virus] ... (*Gwandoya's wife, KAF24 interview*).

The findings of this study suggest that some caregivers for PLWA were at risk of contracting HIV/AIDS through exposure caused by lack of basic necessities for personal care.

5.4.2.3 Emotional difficulties

Caregivers reported in the study that they had many needs and emotional difficulties which were closely related to the unrelenting nature of caregiving. Several factors played a contributory role. Household poverty was a major concern. Conditions of caregiving were generally poor, and participants experienced emotional difficulties in caregiving. To illustrate further, I will draw from interviews with families who lived in a profoundly poverty-stricken setting. Some of the participants – caregivers for Ddamba, a 45-year-old man, Kizza, a 28-year-old man, Amandua, a 20-year-old man, Kibuuka, a 43-year-old man and Okello, a 40-year old man – all had difficulties related to caregiving in a lacking environment in which they could not meet the patient's expectations. For example, Ddamba's wife describes her sense of dissatisfaction in her caregiving which lead to her feeling discouraged. It is evident from her story that Ddamba's family is barely surviving from charitable support from friends. Ddamba's wife describes how her husband leaves home in the morning and walks around the city in search of friends to support him. He then returns home tired and expects a lot of support from his wife, who is also ill (*KAF17 interview, Table 5.13*).

Table 5.13 Emotional experiences of caregivers

You see, sometimes the patient [husband] becomes disappointed and gets stressed ... at times, to those around him; he feels like you have not done much to help him the way he feel and wants. You see we are human beings and we cannot be perfect; even at home there are problems like, now, sometimes the patient feels very tired after walking around all day in town in the hope of getting something for us and at times he has not got someone to give him anything. You see, if he gets home and also does not get what he wants [food etc], he can say to himself 'now what is wrong with this person ... she is not supporting me and knows I am sick' (*Ddamba's wife, KAF17 interview*).

I have my family as well, so adding to the responsibilities has not been easy ... It is stressful, especially when the patient needs something or transport to go for treatment and it is not there ... the only challenge is that my husband is a 'boda boda' man [motorcycle transport business common in Kampala city] and he gets like Ush. 5,000 per day [one pound, thirty pence] and he leaves for us only Ush. 2000 [70 pence] per day for food and to take care of him. We are squeezed in this house: as you can see, a one-bedroomed house with two families in it (*Kizza's sister, KAF04 interview*).

The experiences of Ddamba's wife were echoed in other cases. For instance, Kakiiza's sister's story shows how overwhelming the burden of care can be. With no support, she says it is quite hard to meet the patient's needs. Her story is similar to other caregivers and reveals how hard it is to support the patient's needs: food, transport and basic necessities without money (*KAF08 interview*).

To further illustrate the experiences of emotional difficulties, I will use a case study of Nankoma. Both Nankoma, a 39-year-old widow and her step-sister were emotionally stressed due to a number of factors. Her situation was made worse when her husband died. She was forced to leave her marital home and rejoin her parents. Traditionally, in an African context, Nankoma was supposed to be supported and acknowledged as a widow who has a right to live where she got married. Together with that, she is entitled to ownership of their properties including house or land and any assets or savings she had with her husband. In her case, it was the opposite: she was forced to leave and return to her parents. However, upon her return, she did not get much support from her parental home; this worsened Nankoma's symptoms and she died

shortly after enrolling with HAU. Several factors contributed to her complex situation. One is that her father was polygamous and the family was therefore extended and seemed to struggle to meet their needs due to profound poverty. From my observation, Nankoma was left with little support from her family and lived in an old, abandoned building which was 'not fit' to live in. She was attended by a young girl whose relationship with Nankoma I could not establish. The young girl was not strong enough to support Nankoma and looked depressed and tired during the visit. I learnt that she was receiving instruction from other family members. The child was observed breaking into tears as she explained circumstances under which she tried to give support to Nankoma. I could not interview the girl because she did not meet my inclusion criteria but it was clear that she was unable to attend primary school because of her responsibilities. Again, this situation brings into question the role of gender in palliative care needs and management.

5.4.2.4 Experiences of support by and for HIV/AIDS partner

The study shows that there were marked differences between participants who had HIV-positive partners and the rest. Eleven participants had partners who also had HIV/AIDS in different stages. Experience of living with HIV/AIDS among the HIV-positive couple was associated with unique challenges. The experience of support by and for an HIV-positive partner took several dimensions. The common challenges depended on the stage of HIV/AIDS for the patient and partner, available support, perceived unmet needs and handling of family responsibilities. Unfinished tasks and plans for the future, especially for children, were their greatest challenges. This was

mostly seen in regard to experiences of support and socio-economic status, since household poverty was more profound among the couples with HIV/AIDS. From the study, it shows that the difference could be attributed to expenses related to treatment or AIDS-related costs, which were higher among HIV-positive couples as compared with other participants. Added to that was the fact that most HIV/AIDS partners had no source of income and support. Quite often, perceptions of inadequate support among HIV/AIDS partners dominated the narratives of most participants. In some cases, participants were left to struggle on their own, either because their partners were very weak or separated, or in some cases died. Above all, the socio-economic impact of HIV/AIDS was mostly felt among the 11 participants who had HIV-positive partners. For example, the narratives of some participants¹⁹ revealed the great challenges which stemmed partly from having an ailing or weak HIV-positive partner. Similar concerns were voiced in other cases. For example, Ddamba, a 45-year-old man, and Kibuuka, a 43-year-old man, show great difficulties related to lack of support and dissatisfying support from their partners (*Table 5.14*).

For purposes of getting a more in-depth understanding, I will use a few cases falling in this category to describe the experience of living with an HIV-positive partner. Ddamba's wife, for instance, in her story shows how they are struggling to make ends meet due to profound poverty. Whilst she is trying her best to support her husband (Ddamba), she feels that she is not appreciated. Unmet needs dominate in her story of caregiving. While interviewing this couple, I found that they looked emotional and had a lot of expectations about receiving help from me. HAU later provided them with

¹⁹ Namugera, a 28-year-old man, Musoke, a 25-year-old man, Lutalo, a 38-year-old man, Kizza, a 28-year-old man, Agaba, a 40-year-old female, Ddamba, a 45-year-old man, Ssemwanga, a 43-year-old man, Kibuuka, a 43-year-old man, Nakanwagi, a 30-year-old woman, Ssematimba, a 44-year-old man, and Okello, a 40-year-old man.

a basic support kit. The following table (5.14) describes the experiences of support by and for HIV/AIDS' partners/participants.

Table 5.14 Experiences of support by and for HIV/AIDS' partners/participants

You see, sometimes the patient becomes disappointed and gets stressed ... at times, to those who are around him, he feels like you have not done much to help him the way he feels and wants. You see, we are human beings and we cannot be perfect; even at home there are problems, like now, sometimes the patient feels very tired after walking around all day in town in the hope of getting 'something' for us and at times he has not got someone to give him anything. You see, if he gets home and also does not get what he wants [food etc], he can say to himself 'now what is wrong with this person [herself] ... she is not supporting me and knows I am sick' (*Ddamba's wife, KAF17 interview*).

I was really feeling down and ill but I have improved a bit, though I have not fully felt alright. I am still feeling ill and experience body aches. I have not found any support for food and transport, I am still struggling ... Haa ... they have done testing six times and they have not got it. Even here [in the hospital at Mulago] they have also tested her [his wife] but nothing ... Only all the children have not been tested (*Okello, KAM09 interview*).

I didn't tell my wife, she realised later. When you realise you don't say it easily ... When my other wife died is when she realised (*Gwandoya, KAM24 interview*).

He didn't tell me, now you would know what is going on because we have seen some people with HIV/AIDS. His mother and one relative told me: 'You are seeing the situation; go and check yourself [test for HIV/AIDS] and see if you are sick [infected]. You can begin to take the medication because you have seen how the things are.' Then I went to the hospital in X area, you know the hospital ... That is where I went ... They asked me what has pushed me to come here. I told them that my husband is bedridden and therefore I want to know my status so that I can start taking medication (*Gwandoya's wife, KAF24 interview*).

The problem I face is mostly looking for money to help me travel/transport to hospital in that way. When I get at least Ugsh 200 (1 pence) I can eat tomatoes like that ... Most of the time when I get like Ugsh 5,000 (1 pound 50 pence) I keep like 2,000 but if I see that it won't be enough I go to my friend or brother and he gives me what he can, although they are all not so well off, so they all help me in different ways. Another thing that has been disturbing me is skin [KS] – this is my main problem. And I also stopped meeting with my wife [having sex]. I don't know why she refused but when she refuses I left her alone because when you nag her you can begin fighting (*Kibuuka, KAM25interview*).

In other cases, participants expressed as above 'dissatisfaction with support' from their partners. For example, Okello a 40-year-old, feels that he is not getting much support from his wife and now struggles a lot (*KAM09 interview, Table 5.14*). He reported that he had slightly improved after enrolling into palliative care but still

encountered challenges related to support, which was extremely limited. He relied completely on HAU for support. I observed that HAU were helping those individuals who had barely any resources to support themselves, and Okello was among these beneficiaries.

Some participants who did not disclose their status to their partners kept their partners in a state of worry and uncertainty. This situation was very stressful to some who did not know their status. For instance, Gwandoya, a 32-year-old man in stage IV, is a polygamous man who intentionally did not disclose to his wife. His first wife died of HIV/AIDS and he remarried, subsequently infecting the second wife (*KAM24 interview, Table 5.14*). His second wife is angry and reports how she has lived in fear and worry about her status for a long time. Prompted by fear of contagion, she went to be tested for HIV. When I visited them, the wife had just received the outcome of the test and she was in HIV/AIDS stage II.

Another challenge related to the experience of changing roles. This was especially difficult if the patient was the breadwinner and had dependants. Findings of this study suggest that challenges were related to task-shifts following the ailing partner. As seen in the cases of the participants described above, the experience of living with a partner who is HIV-positive is not only emotionally taxing but also associated with less support to the patient. Thus support by and for the HIV/AIDS partner is quite complex and strenuous, especially if both partners are weak. I observed that poverty was scaled up and most felt amongst HIV/AIDS couples. The AIDS scourge greatly threatened every sphere of their lives: economical, social, psychological and sexual among partners with HIV/AIDS.

5.4.2.5 *Anxiety in the last days of life*

Eight patients who participated in the study died during the course of the study. Among family members who nursed their patients, they had anxiety which was evident. It was especially common when the dying person was being nursed by the family or when they were in acute care and breathless. During my research study, family members and caregivers reported feelings of sadness, anxiety and often depression as they observed their beloved one draw towards dying. To illustrate this observation, I have cited experiences of a few family members who nursed participants who died shortly after they were enrolled into the study. Family members²⁰ of each expressed anxiety and feelings of helplessness at some point. Lost between what they could still do and for how long seemed to preoccupy most caregivers during the last days of life of their relative. When I visited Adongo's daughter, for instance, she seemed to feel helpless since her mother appeared to be deteriorating. In her grief, Adongo's daughter describes end of life experiences of her mother, who died shortly after an eight-week period of study. She was saddened by her mother's state of deterioration and becoming weak, despite having been on treatment. Table 5.15 describes some of these experiences.

²⁰ Mugagga, a 31-year-old man, Mugume, a 45-year-old man, Wandira, a 30-year-old woman, Ssalongo, a 33-year-old man, Adongo, a 44-year-old widow, Nalongo, a 29-year-old woman, Nankoma, a 39-year-old widow, and Nabulungi, a 47-year-old divorced woman.

Table 5.15 Experiences of end-of-life days: joint account of patient and caregiver's interviews

Recently, like two weeks, she is no longer improving like it was ... even the weakness ... but when we had just come from the hospice she was still strong (*Adongo's daughter, KAF07 interview*).

You see my hair is going off as a result of taking ... the other day they discharged me. I told doctors that I have started taking it and the doctor said it is good and, when they changed the treatment, they gave me another drug, not the first one ... by the time I got off the bed I had some little strength but I was breathless, I said Oh God why am I breathing so badly ... (*Nankoma, KAF12 interview*).

I am just lying here. I sleep most of the time ... because I cannot walk now. Health staff from Nsyambya Hospital come visiting monthly and bring me medication [including HAART]. Today, I feel so ill [sweating and breathless, lying in his bed]. I came from hospital last week and it seems I may again today. I am using these drugs but not improving ... (*Namugera, KAM06 interview*).

Nankoma, a 39-year-old widow, who died shortly after four weeks in the study, describes her experiences of her last days. In her story, she experienced serious side-effects of chemotherapy, which included hair loss, and she suffered from breathlessness, which necessitated frequent hospitalisation. Nankoma experienced complications relating to advanced AIDS as well as chronic serious side-effects of medication. Her health continued to deteriorate, and her last days were spent in the hospital's acute unit for oxygenation (*KAF12 interview, Table 5.15*).

Namugera, a 28-year-old man, who died shortly after six weeks in the study, narrated the story of his last days. I have described his life in detail in Chapter Four. However, in this section, I will only illuminate his brief experiences of those last days. Having not disclosed to his wife, Namugera's health continued to deteriorate with frequent hospitalisations and less support, since no one knew of his illness except medical staff. In fact it was a challenge to strike an appointment with him because, by the time I was due to visit him, he had either moved to hospital or he was acutely ill. During the interviews, he had respiratory distress and several episodes of breathlessness. Since he

was unable to walk due to chronic STI, a special taxi was hired to transport him to hospital each time. He kept himself indoors most of the time because of the stigma of his illness. During my visit, his neighbours did not know whether he still lived in the same place since he had stopped interacting. He did not live long, as he succumbed to AIDS complication and died (*KAM06 interview, Table 5.15*).

5.5 SOURCES OF HELP AND SUPPORT

In this section, participants' sources of help and support will be described other than that provided by the family. The main sources of non-familial support included HAU, religious agencies, and AIDS agencies other than HAU. The kind of support participants got from these agencies covered material help (subsistence food, hygienic items), emotional support, medical support (CD4 count support, HAART supply, medication for opportunistic infections), regular visits, and transport during acute times.

5.5.1 Palliative care service delivery: HAU experiences

All participants in this study experienced pain and distressing symptoms related to advanced HIV/AIDS (*Appendix XI*) and therefore enrolled for palliative care services in HAU (*Appendix XII*). In their interviews, it emerged that, although each participant experienced some form of positive impact, for some, this was short-lived while, for others, it was relatively long-lived. For instance, Masani, a 48-year-old woman in

stage IV (AIDS), in her story describes palliative care services as having improved her condition and now she was able to interact with people because her foul-smelling fungating wound had been well managed. Similar views were voiced by another participant. For instance, Musoke, a 25-year-old man, describes in his story how he has improved following commencement of palliative care services. He has regained back his lost strength and his pain has been managed with morphine. He is now trying to resume his previous duties. There are further insights into these findings (of impact of care on PLWA) in Chapter Six, where I have reported findings of measurements of outcome of care using the APCA African POS tool.

While the majority of patients reported improvement mainly in their physical condition when they enrolled for palliative care services, others did say that they felt HAU supported not only their physical needs but also their basic needs for subsistence. For example, Nabirye, a 24-year-old single woman, reported the benefits and support she got after she sought palliative care services from HAU. She recounts her experiences and how she is grateful for support from HAU. The majority of participants reported that they experienced improvement in pain and symptom control. For example, Ddamba, a 45-year-old man, describes that the distressing symptoms in his advanced HIV/AIDS stage have reduced. He describes how he experienced some side-effects, which did not last long. He feels better now and appreciates the palliative care drugs.

Some of the participants expressed their views of having been supported from HAU. This kind of support means basic survival and transport to access treatment. Among those who featured in this category include Kizza, a 28-year old man, and Gwandoya, a 32-year-old man in stage IV, just to mention two. In their interviews, they each had

a similar experience of having been supported with basic necessities, including food as well as transport, offered to enable them to access palliative care drugs. It emerged that HAU is supporting those who are barely surviving and lack family support. While this was the case, it was generally observed that the support offered by the hospice was not sufficient and did not extend to the caregiver; the patients and family continued to live with a shortage or lack of food and basic necessities (*see Table 5.16*).

Table 5.16 Support experiences

I came to the hospice because I knew they would give me medication to reduce the pain of cancer because, even after getting treatment in Hospital X, you still feel the pain; cancer is what made me come to the hospice because the HIV issue was being worked upon since I joined I had so much pain but it has reduced. The wound [fungating AIDS-related cancer wound] was so painful, but now it is only 'paralysed' but not painful. I used to experience lots of pain and did not have specialised care, but now I get visited like now you have come home. I am always lonely since my daughter is married and I am alone here (*Agaba, KAF05 interview*).

But even with all these drugs [showing me] they have been giving me, even if I take them the symptoms were still not going. But since I came here and I was given some treatment, at least there is some improvement and I don't have diarrhoea so much ... You the hospice, when I come to you, you take care of me and you give me some assistance because some hospitals you go no one takes care of you and no one cares and your illness gets worse ... (*Nabirye, KAF18 interview*).

There has been a big improvement, even people notice ... I am able to interact with people now and move around. I feel good about myself now, since I am no longer smelling ... It is not like the last time ... not like that time ... leaking ... (*Masani, KAF23 interview*).

When I started the drugs from the hospice, it gave me problems at first in the area of passing bowel [constipation]. Then I was given more drugs and kept increasing the amount from one to two to three ... then the problem stopped. I see now that I have not many problems. In fact I have been surprised because I am not a visitor now. Since I joined the hospice I have been handled well, especially with my coughing a lot. I was given some drugs which improved my condition (*Ddamba, KAM17 interview*).

Now you see the other pain has reduced and now I can sleep ... because of the other medicine you gave me ... [morphine], I found morphine and counselling important at the hospice. I used to have ... what I can I say it makes your face ... depressed ... like fear ... but now I'm feeling better. You see, like now in the morning, I woke up and I had nothing to do ... then I was trying to make a table in the workshop ... Even when I go back to Kabale ... I can dig ... as you have found me working in the workshop and even go back to school. I don't have many problems, only the problem of this lesion in my leg [KS]. At first I became scared ... It was a nightmare, but when I got some information from counsellors I got a little better. Sometimes, like August last year ... I thought I would die quickly, those ideas ..., but now I feel I would feel ... What made me strong since then ... I see after taking the drugs [HAART] properly

I feel power ... and also see they [parents] have interest in me – they can still pay school fees if I go back to school. I thought that they might not give me school fees. I was scared of that; they told me that, even if you are HIV-positive, we will still support you (*Musoke, KAM29 interview*).

Last time you came you gave me some sugar and now it is finished and you know now I am not working and I am not leaving the house. I have backache and I have nowhere to get it ... (*Gwandoya, KAM24 interview*).

Though I may want to work, I don't have help. Any work I can do, for instance, before I was dealing in buying and selling of bananas but now there is no money. I want the hospice to assist my child, especially with school fees, because the father died and the child has no help. I don't have money to take him to school (*Kakiiza, KAF08 interview*).

If it was not for the leg you would see a difference. The legs make me immobile and then lose appetite ... When the pain comes, even if I take that whole green bottle,²¹ the pain is still there ... I will tell you the situation I am in because before I was in a very bad situation but now I see a difference, though only the leg that is doing bad ... if there is a way I could get help then I would live because I don't work, I don't walk, I don't have any plan and I don't have money. With that it is you [referring to researcher] who will show me the way forward. I wonder what I should do and I am hoping to get the plan or help from you (*Kibuuka, KAM25 interview*).

Some participants had unrealistic expectations from HAU and, as such, lived with hopes that the hospice would address all their needs, including provision of school fees for their children. For example, Kakiiza describes his problems of lack of fees with the hope that he would be assisted in school education for his children.

Social support from health care staff has helped some PLWA live positively with HIV/AIDS. For instance, Musoke, who dropped out of school and disappeared from home to be a street boy in the streets of Kampala, attributes his ability to cope with the disease to the staff's counselling and his parents' committed love and care (*KAM29 interview, Table 5.17*).

In other instances, HAU collaborated with other external agencies in order to address other needs. In such cases, participants got support from several AIDS agencies which offered specialised services. Some of the agencies involved were Mulago Hospital,

²¹ Liquid morphine reconstituted and packaged in bottle. Colour matches with concentration; green is the less concentrated.

Cancer Unit, The AIDS Support Organization (TASO), Infectious Disease Institute (IDI), Mulago, Kampala, Mild-may organisation, radiotherapy and the CD4 count monitoring unit at Mulago. For example, Nankoma, a 39-year-old woman describes how she got support from the Cancer Institute, though she suffered side-effects (*see Table 5.17*).

Table 5.17 Support from other agencies

You see my hair is going off as a result of taking. The other day they discharged me. I told the doctors that I have started taking it and the doctor said it is good and they changed the treatment, they gave me another one [drug], not the first one which now improved my body. So now I will go back on 17th May, which will be Thursday or Friday to Mulago Cancer Institute ... (*Nankoma, KAF12 interview*).

You see I started HAART like a month ago but have been off for three months ... After going to doctor X for chemo ... I could not walk but after injection I was okay. The ARVs had not made any change. I get ARVs from IDI [Infectious Disease Institute]. My brother helps me in transport. I am with him most of the time ... (*Lutalo KAM02 interview*).

In this illness, without telling lies, from the time I started going to the Infectious Disease Institute [IDI], I have not bought any medication [HAART], but at cancer [Cancer Institute Mulago] I have not taken any medication for free; it is for buying ... the cancer one. I like hospice also for giving me the morphine which I also don't pay ... (*Kibuuka, KAM25 interview*).

... see also they [parents] have interest in me; they can still pay school fees ... I thought that they might not give me school fees ... again they [parents] had to try hard to bring from Kabala to Mulago Hospital for treatment ... my sister here is looking after me ... and also you doctors, you have helped me ... like the other time when you gave me drugs now the other things which were painning me stopped. Counsellors also have been useful because if they were not there from that time till now I would still be living in fear. I am now ok, I don't have much trouble (*Musoke, KAM29 interview*).

The following section discusses these findings of experiences of living with HIV/AIDS in relation to the wider literature.

5.6 DISCUSSION

5.6.1 Introduction

This chapter has reported on participants' varied experiences of living with HIV/AIDS. In this section I discuss the findings of the study within the context of the wider literature. Several factors shaped the experiences of PLWA including contextual, environmental and socio-demographic characteristics such as: age, gender, socio-economic factors, relationship issues and availability of support. In this discussion section I will highlight briefly the themes reported in this chapter before discussion.

First, in the area of physical experience of living with HIV/AIDS, the chapter shows how patients' reports of distressing symptoms and pain were an outstanding feature of their interviews. Patients suffered from symptoms associated with advanced AIDS (stages III and IV): KS and opportunistic infections. These experiences were compounded by other factors, notably poverty and accessibility of medical treatment and palliative services.

Second, a range of psychosocial issues were reported that patients encountered as they lived with HIV/AIDS. These include the stigma of having HIV/AIDS disclosure issues among PLWA. AIDS was particularly evident in relations with family members. To some family members, individual stigmatising experiences led them to feel rejected, while some assumed self-imposed isolation to avoid interacting with others. In some cases, the health status (of some family members) was kept a secret affair, while some avoided even discussing it. They sort of chose 'silence' as a

strategy to live with HIV/AIDS to keep it confidential. Some patients preferred not to discuss their status with family members. However, where they perceived benefits outweighed costs, they chose a particular means of conveying the message (disclosing). Handling children's curiosity was a challenge in disclosure.

Third, spirituality emerged from the interviews as a coping strategy among some terminally-ill patients in this study. The majority of patients who viewed life this way had linkages with churches, pastors and prayed a lot. Apparently, patients in this category got some valuable support/assistance from faith-based organisations, which helped them to live positively. Some church members offered to help in several ways: while some paid warm visits and prayed with the patient(s), others offered hope and oriented patient(s) with their solemn beliefs/creator. Church rituals were also offered to some patients especially those who were in an advanced stage.

Fourth, experiences of caregivers taking care of their relatives do reflect great challenges of caregiving. This study reports the emotional burden of caregiving, and the experience of partners who also have AIDS giving support and care. As for support and care by and for PLWA, there were reports that generally the nature of support was an unsatisfactory one: there were many expectations, especially from the patient. Caregivers who often had AIDS were also ill and could not support adequately their partners (patients), while socio-demographic characteristics of some just put them at a disadvantaged level. Some caregivers were young, while others lived in poverty, and all experienced an emotional burden in their caregiving.

5.6.2 Socio-economic impact of HIV/AIDS

To begin with, in this study, the findings reflect the socio-economic impact of HIV/AIDS in society. The majority of the participants were unemployed and living in poverty; they reported a marked decrease in household income as a result of illness (*see Table 5.13*). The present study builds on work of previous studies (Loewenson, Hadingham & Whiteside, 2009; Salinas & Haacker, 2006; Stoltz, Tekola et al., 2008 Willman & Uden, 2006); however majority of those studies done concentrated on socio-economic impact of HIV/AIDS. The present study showed the experiences of living with HIV/AIDS and household poverty as accounted by patients and their family members in chapter 4.

While it emerged through interviews that patients with advanced AIDS were living in poverty, HAU and other AIDS organizations supported the needy patients. Studies reviewed on socio-economic impacts of HIV/AIDS did not report efforts or interventions which the present study has unveiled. However, the present study lacked comparative view or longitudinal aspect of follow up patients with advanced AIDS to establish socio-economic impact of HIV/AIDS. Other studies reviewed have reported on specific aspects of the impact. For instance, in a recent longitudinal study in South Africa about the economic impact of HIV/AIDS, 12 households in repeated observations over a year reported HIV/AIDS exhausts the financial capacity of households (Hosegood *et al.*, 2007). A similar study from the Ivory Coast found that HIV/AIDS had a drastic impact on household poverty. However, the latter study reports that households with HIV/AIDS spent twice as much on medical expenses than any other household (Tekola *et al.*, 2008), and further reports that indirect costs of HIV/AIDS for patients and caregivers were severe for the household. A cross-

sectional, multi-countries comparative study to evaluate the significance of HIV/AIDS in household poverty reported significant differences in the economy of households affected by HIV/AIDS as opposed to non-HIV/AIDS households (Booyesen & Arntz, 2003). Further, households experiencing HIV/AIDS deaths are poorer than those experiencing a non-AIDS death. Still, in another study, the findings report that poorer households experienced a greater decline in socio-economic status (SES) following the death of a household member (Tekola *et al.*, 2008).

In this study, as a result of the socio-economic impact of HIV/AIDS on many households, some participants reported that they now connect with their family clan system, which was regarded as a significant form of support. The majority of the family caregivers were part of a larger 'clan' system. The clan was significant in my study because some patients chose to disclose to distant relatives who lived far away, for example in urban areas, for purposes of support. Particular cases were described in which it was clear that PLWA sometimes sought help from clan members who reside in urban areas in order to access HIV/AIDS services. Clan members supported different participants with shelter, food and basic services, transport to hospitals and in some cases money to buy medications. Whilst some studies have reported similar findings (Ankrah, 1993; Gillies, Tolley & Wolstenholme, 1996), these studies did not take into account experiences of patients living with advanced AIDS and their caregivers which this present study has unveiled.

Further, the findings of the study reflect a particular socio-economic impact of HIV/AIDS on women. The impact on women is confounded by socio-cultural-related factors. For instance, some of the female participants were married or were widowed. Regarding widows, they faced challenges of either returning from where they got

married for lack of support or suffer lack of support. A particular case study captured emotional difficulties as reported under the heading: 'emotional difficulties' in section 5.4.2.3 of this chapter. All these experiences related to land issues with regard to widows. As such, women participants who were once married but are now widowed lived in fear and uncertainty of the potential threat of being forced to leave as soon as their husbands died. Some participants had already been evicted and were now living in their parental home. For some, whose husbands were still alive, they expressed a lot of worries about future uncertainties. Previous studies (Cote, 1991; Spirig, 2002; UNAIDS, 1999), show how gender plays a significant role in determining women's and men's relative access to care and social support, often exacerbating the already desperate and dire consequence of HIV/AIDS. However, these studies did not report experiences of female patients living with advanced AIDS in resource-poor setting and accessing care and support which this present study has added. Whilst cross-sectional study reported that having HIV/AIDS in one way means losses of a psychological nature, physical nature and social nature (Spirig, 2002), the present study has added new insight into socio-cultural dimension of experiences of female patients living with advanced AIDS.

A review of the literature shows there is much more of a socio-economic impact of HIV/AIDS on women (Shacham *et al.*, 2008; UNAIDS/WHO, 2002). Findings of my study were limited to the HIV/AIDS impact on women who were widows or women who had separated from their husbands and had difficulties accessing support and care. For instance, the wider literature acknowledges the fact that women do suffer a disproportionate lack of support due to HIV/AIDS. In addition, a study by Shacham and his colleagues (2008) sought to identify characteristics of psychosocial support

during HIV-related treatment. This study highlights marital status (living without a partner) and elevated needs among women who do not have a spouse or significant other. This is particularly true with findings of the present study: many women in the study lacked support and depended on outside help. Therefore, there is new insight into experiences of female patients living with advanced AIDS. For instance, this particular group were vulnerable and experienced frequent hospitalisations because of lack of support.

Whilst several studies reviewed (Bondon *et al.*, 1997; UNAIDS, 1999 Salinas & Haacker, 2006) have focused on the gender issues in relation access to care and support, the present study brought in a new insight into dimension of female patients living with advanced AIDS and are widowed or the male head is also ill. For instance, it emerged that women are also likely to be disproportionately affected by the impact of HIV/AIDS when a male head of household falls ill. As a result of the loss of income from a male income earner, women and children may be required to seek other sources of income.

The wider literature shows that women faced proportionately more barriers than men in seeking and accessing care (Salinas & Haacker, 2006; UNAIDS, 1999). For instance, in the Ugandan setting, a woman rarely holds land in her own right and, if her relationship with the male landholder is severe, her position – and perhaps also that of her children – is likely to be precarious (Bondon *et al.*, 1997). Gender, furthermore, is a significant player in determining how woman and men are able to cope with the impact of the epidemic in terms of economic effects, access to care and

support (UNAIDS, 1999). Girls are likely to be pulled out of school to fill the gap in food production in instances where outside workers cannot be hired due to the depletion of household economic resources (Bondon *et al.*, 1997; UNAIDS, 1999).

Findings of this study suggest that the majority of participants faced hardships and lived in widespread and characteristic conditions. These conditions added to vulnerability of PLWA to weight loss and wasting that is associated with opportunistic infections. Some of these opportunistic infections result from low immunity due to not only the disease process but also lack of adequate nutrition. The present study reports that food security among PLWA was threatened and many survived barely on a one-course meal per day. Food consumption and nutritional status of PLWA according to the study was highly affected by the incapacitating nature of advanced AIDS. Most of the participants were now bedridden, unproductive and with many dependants. The situation was also confounded with poverty and lack of support, which further complicated the situation. Whilst the findings of the present study were in line with previous studies (Kuria, 2009; Lemke, 2005), there was new insight into experiences of patients living with advanced AIDS and in poverty. The present study describes how these vulnerable groups lived and their stories have captured in the pen-portraits (chapter 4) and introduction of this chapter which adds new understanding into experiences of PLWA.

Some PLWA in the present study reported chronic dimensions of food insecurity, which is closely linked to poverty and deteriorating socio-economic conditions. HAU supported those who were in this category by providing a small amount of food per week because they lacked food. This observation is supported by a previous study by Kuria (2009) who, in a survey to establish food consumption, dietary habits and

nutritional status of PLWA, reported that the majority of PLWA have little variety of food.

5.6.3 Physical challenges

Whilst the findings of this study supported findings from previous research that living with HIV disease poses extensive physical and psychological challenges for the infected person as well as their family members (Grant & De Cock, 2001; Hirschfeld, 1998; Holzemer, 2002; Makoe *et al.*, 2005; Marcus *et al.*, 2000), the present study has added new insight into how PLWA respond to these challenges. The present study unveiled the experiences of PLWA on access to care, treatment and support to overcome physical challenges. These challenges are profoundly disruptive and impact on every aspect of daily life. HIV/AIDS-related pain is a significant clinical problem associated with functional impairment and psychological distress (Marcus *et al.*, 2000). The high prevalence of pain among patients has been reported in many studies (Borgo *et al.*, 2001; Breitbart *et al.*, 1996; Joachim *et al.*, 2007; Marcus, 2000). In this study, participants experienced pain in the context of other AIDS symptoms, especially persistent fatigue. Whilst other studies have reported similar observation (Joachim *et al.*, 2007; Voss, 2005; Voss *et al.* 2007), the present study adds new insight into understanding PLWA and their experiences in the last stages of living with advanced AIDS.

Participants experienced multiple distressing symptoms resulting from advanced AIDS (stages III and IV). This observation was in line with other studies (Joachim *et al.*, 2007; Makoe *et al.*, 2005), however, the present study did not measure the

prevalence and incidence of pain and distressing symptoms to establish the magnitude. For instance, studies found that up to 85% of HIV/AIDS patients complain about periodic or persistent moderate to severe tiredness and exhaustion, while in other studies the incidence of pain ranges from 30%-90% (Joachim *et al.*, 2007; Makoaet *et al.*, 2005). It emerged from interviews that the experiences were worsened by presence of opportunistic infections and AIDS malignancies. This finding is supported by previous studies (Nonhlanhla *et al.*, 1995; Tsai, Hsiung & Holzemer, 2002), however the present study adds new insight into experiences of living with HIV/AIDS in resource-poor context. These contexts shape experiences of access to treatment and care for opportunistic infections and prevalent malignancies among patients with advanced AIDS. Other studies have documented pain, and AIDS symptoms are quite distressing and significantly impact on psychological wellbeing and quality of life (Jean *et al.*, 2009; Jennie, Tsao & Soto, 2009).

5.6.3.1 HAART

The participants in this study were all residents of Kampala environs. Congruent with a previous retrospective cohort study in Kampala (Abaasa *et al.*, 2008), the majority of participants (approx 70%) were on HAART and accessed treatment from various HIV/AIDS care programmes in Kampala. Whilst the majority of participants on HAART reported positive outcomes of treatment, some experienced distressful symptoms because of its side-effects. Whilst these findings are supported by previous studies (Cooper *et al.*, 2009; Preau *et al.*, 2007; Raveis & Sacajiu, 2009; Sankar *et al.*, 2006), the present study has added insight into how PLWA and on HAART still need palliative care to improve on distressing symptoms. The findings particularly showed

that having HAART only as a therapeutic treatment for PLWA left patients with some palliative care needs unaddressed (Harding, 2004, 2007; Harding *et al.*, 2005; Raveis & Sacajiu, 2000). This is particularly true with the present study, as narrative accounts of participants supported these findings. Some participants took ARVs irregularly; some endured, while some rejected them completely. For some, they had to combine them with traditional medicine in order to overcome distressful symptoms.

On the one hand, it is evident that adherence to HAART is important for treatment success and increased survival (Chesney, Morin & Sherr, 2000; Fairley & Grierson, 2007; Jelsma *et al.*, 2005; Klitzman *et al.*, 2004; Merzel, Vandevaner & Irvine, 2008; Murphy *et al.*, 2000; Proctor *et al.*, 1999). On the other hand, it further complicates the disclosure issue as some may not see the need. This is because, with the success treatment rate, the body improves and individuals return to normal activity. As such, someone do not see the need to disclose status. The present study has limited findings to support this new dimension of the course of disclosure with the advent of new medications worth further exploration. However, another study has picked up this dimension (Klitzman *et al.*, 2004), which is worth exploring.

The experiences of interplay of HAART on PLWA have been described vividly in their narratives. Indeed, with new treatment, additional symptoms and complications such as pain have been introduced. This new aspect may call for further understanding of models that will manage it well in an African setting. Supported by previous studies (Jelsma *et al.*, 2005; Makoe *et al.*, 2005), the present study showed multiple aetiologies of AIDS symptoms, even amongst participants on HAART, which need to be addressed contextually.

5.6.4 Psychosocial issues

5.6.4.1 Decision to disclose

Findings of this research suggest that disclosure among PLWA was a sensitive issue. Studies done on disclosure among HIV/AIDS patients report critical issues related to decision to disclose (Arnold *et al.*, 2008; Bogart *et al.*, 2008; Brown *et al.*, 2003; Chandra *et al.*, 2003; Greeff *et al.*, 2008; Holt *et al.*, 1998; Klitzman *et al.*, 2004; Lee & Johann-Liang, 1999; Makoe *et al.*, 2008; Medley *et al.*, 2009; Pilosky, Sohler & Suseer, 1999; Serovich, Craft & Yoon, 2007; Smith, Rossetto & Peterson, 2008; Vallerand *et al.*, 2005; Wouters *et al.*, 2009). The emphases of these studies are on sensitiveness of disclosure among PLWA, which causes stress and apprehension due to uncertainty about how people will react to it as well as its role in coping with HIV/AIDS. While disclosure is seen to be imperative leverage for support (Dlamini *et al.*, 2009; Kalichman *et al.*, 2003; Serovich, 2007; Shacham *et al.*, 2008; Wouters *et al.*, 2007), in a recent cohort study of PLWA in South Africa, Wouters and his colleagues (2009) reported disclosure as necessary for material and emotional support from significant others.

In contrast, another study suggests that disclosure does not guarantee an increased level of support, even from family members; instead, patients encounter difficulties related to stigmatisation, rejection and abandonment (Dlamini *et al.*, 2009). Other studies have reported prejudice and stigma (Hoyt *et al.*, 1997; Kumar *et al.*, 2006; Vallerand *et al.*, 2005). Presented with such dilemmas, patients face challenges of disclosure with conscious acts of balancing consequential risks and benefits of keeping sero status secret. However, a cross-sectional study seeking characteristics of

psychosocial support of PLWA during their treatment suggests difficulties in accessing available and culturally-sensitive psychosocial care amongst those patients who sought such support (Dlamini *et al.*, 2009). The present study further suggests enormous psychosocial distress, which varies across all stages of HIV/AIDS. However, in line with findings of this study, other studies done in Uganda suggest use of diverse coping strategies including spiritual and other social community agencies to overcome psychosocial difficulties (Kadowa & Nuwaala, 2009; Medley *et al.*, 2009; Otolok-Tanga *et al.*, 2007).

Some participants in the study used various strategies to disclose. Strategies used include use of indirect approaches, use of intermediation, use of trusted confidants and, in some cases, non-disclosure for fear of rejection (Antelman *et al.*, 2001; Greef *et al.*, 2008; Painter, 2001). The studies done in an African setting take into consideration the context of collective societies, which are more concerned with the harmony of the group. Therefore, some participants prefer an indirect approach in disclosing their status to avoid hurting hearers. The approach also takes into account the cultural background of communication in an African setting, which also emerged as influencing strategies of disclosure (Kadowa & Nuwaala, 2009; Miller & Rubin, 2008). Participants who experienced difficulties disclosing employed different technical uses of language, which had overlapping meanings. The findings on communicating issues related to disclosure emerged to be so sensitive that among those participants who disclosed were some that had received counselling. This finding is supported by a recent case control design study to explore factors influencing disclosure in one of the districts in Uganda (Kadowa & Nuwaala, 2009).

The study suggests measures to empower PLWA to disclose, such as improved communication skills which should be reinforced during the counselling session.

In my view, disclosure depends on several psychosocial factors such as gender, anticipated support or negative consequences and psychological distress. Disclosure seemed to happen at some time between diagnosis and the end of life period for purposes of accessing care and treatment. However, delayed disclosures may be associated with poor coping, which may complicate illness. Thus, varied predictors of disclosure in a resource-poor setting need to be understood if disclosure among PLWA needs to be addressed.

Other participants in the study reported difficulties in handling disclosure among children. Findings of this study show that the process of disclosure is stressful and, though the decision to disclose is so individualised, the subject would rather be avoided because of its sensitivity. Pilosky and his colleagues argue in their parental disclosure interview that there is disagreement about several aspects of disclosure of HIV status to children (Pilosky, Sohler & Suseer, 1999). Their study suggests that there is no unanimity as to whether children can benefit from parental disclosure. It is therefore against such understanding that some parents-participants in the present study who did not disclose their status to children used simple health terminologies while referring to HIV/AIDS disclosure. Terms used to refer to the illness of their parents who had HIV/AIDS were, for example, 'doing poorly' or 'ill'. Findings of this study supported use of elusive discussion frequently when an issue of disclosure arose among children of HIV-positive parents. This observation adds new insight into how parents handle the issue of disclosure among their children. Whilst it has been explored in a longitudinal descriptive study examining mother-to-child coping and

adjustment, which suggests unique processes of disclosure to children (Lee & Johann-Liang, 1999), the present study revealed non-specific reason as to why parents did not disclose to their children. Lee and Johann-Liang's study suggests hesitancy in discussing the disclosure issue with their children. The study further reports that many parents or caregivers do not want to tell the children or others details of their illness because they are 'not old enough' to understand the disease and they keep the diagnosis a secret. Thus, when disclosure issues arise, HIV/AIDS need not be the first and foremost words to the child. Whilst child's developmental level was cited as the main reason given by mothers in choosing to disclose or not to disclose (Lee & Johann-Liang, 1999; Vallerand *et al.*, 2005), the present study reported did not raise similar issue as a barrier to disclosure. Unlike another study where some members decided to disclose whenever it was perceived to be a 'burden' to their children (Lavick, 1994), the present study did not report similar experiences. These experiences in Uganda add new insight into how parents living with advanced AIDS handle disclosure in different contexts.

Notably, Vallerand and his colleagues reported the stigma and societal misconceptions associated with the disease, and the fear that their children would not have been able to handle the information (Murphy *et al.*, 1999; Vallerand *et al.*, 2005). However, the present study did not establish this particular aspect though it emerged that parents were not ready to share their status with children.

A study by Chandra and her colleagues reported several factors that may influence decisions of disclosure within that continuum in the HIV/AIDS context (Chandra, Jairam & Jacob, 2004). In their study, several factors seem to play roles which include concerns around employment, potential disruption of relationships, avoiding potential

verbal and physical abuse, fear of discrimination, guarding one's self from others, and accessing care facilities, treatment and support services. The study further unveiled that disgrace to self, family members, or neighbours were reported to be the main reasons for non-disclosure.

Holzemer and his colleagues reported that HIV diagnosis and disclosure triggers stigma, especially received stigma (Holzemer *et al.*, 2006).²² Makoae *et al.* (2008) report that disclosure among PLWA is carefully used as a coping strategy, depending on how the participants judge whether it would make things better or worse. Disclosure is therefore used mostly in situations in which PLWA thought disclosure might lead to support from spouses and family members.

A study unveiled that expectation of emotional and material support from family members were commonly cited reasons for voluntary disclosure (Chandra *et al.*, 2003). However, Brown *et al.* (2003) in their study reported that non-disclosure, denial, and hiding could also be a way of coping, especially if it protected someone from stigma. This is despite the burden that comes with keeping HIV secret, which requires someone to lead a double life: having only limited resources and relations, or having to lie (Greeff *et al.*, 2008). The same study reports that information control is an important component of stigma management. Bogart *et al.* (2008) in their study revealed PLWA were less inclined to disclose if they observed prejudicial attitudes among family members and friends who were unaware of the patient's HIV status. It was therefore felt that stigma was used as a basis for the decision about disclosure to individuals. In the same study, the stigma surrounding HIV has been implicated as a

²² Where received stigma refers to all types of stigmatising behaviour towards a person living with HIV/AIDS, as experienced or described by themselves or others.

barrier to HIV treatment adherence because patients may be reluctant to take, carry, or store medications around others who do not know their sero status.

Studies differ as to whom PLWA disclose to. While, in one study (Bogart *et al.*, 2008), a higher percentage of participants disclosed their HIV status to health care workers, sexual partners and family, another study revealed that self-disclosure of the HIV sero status was highest for partners, followed by friends, and the lowest was for family members. Disclosure to sexual partners needs to be facilitated. This present study has therefore added new insight into experiences of not only handling disclosure issue but it has shown that ‘the how’ aspect of disclosure matters. However, factors influencing disclosure in different context merits inquiry. The present study also recommends that counsellor need to empower an individual during Voluntary Counselling and Testing (VCT) to share status.

5.6.4.2 HIV/AIDS stigma

The majority of participants in the present study are reported as having experienced HIV/AIDS stigma at one stage of their illness. This finding though supported by a study in Uganda (Medley *et al.*, 2009), it shows that HIV/AIDS still remains highly stigmatised despite government efforts to reduce this. Holzemer and his colleagues in their study suggest the psychosocial impact of stigma on PLWA is significant (Holzemer *et al.*, 2006). The latter study reports loss of social support, persecution, isolation; job loss and problems accessing health care services resulted from stigma. Similarly, a Zimbabwean study (Duffy, 2005) unveiled suffering, silence and shame as a result of HIV/AIDS-related stigma, while another study (Birds *et al.*, 2004)

reported greater stigma was associated with severity of HIV symptoms and lower levels of adherence to antiretroviral therapy and increased depression. This was particularly true with the majority of participants in the present study who experienced stigma. To some, experience of the HIV diagnosis in their community or families meant loss of support, discrimination and increased suffering due to delineation. In my study, reported here, some participants reported difficulties in living with AIDS which had physically affected their self-body image. It was psychologically stressful to an extent that affected individuals isolated themselves or minimised interactions. Whilst this finding is in line with previous studies on the role of changes of body image in patients with HIV/AIDS (Huang *et al.*, 2006; Martinez *et al.*, 2005; Yebei *et al.*, 2008), the present study described experiences of patients with advanced AIDS and their views on body image changes. These experiences added a new insight into dimension of role of body image amongst patients with advanced AIDS. Some participants experienced enacted stigma similar to a previous study (Maltinez *et al.*, 2005). Among participants in this category, some reported to have changed their behaviour. Some decided to be silent; this has been referred to as a manifestation of enacted stigma characterised by internalised negative perceptions (Bogart *et al.*, 2007; Fisher, 1994; Hong *et al.*, 2008; Yebei, Fortenberry & Ayuku, 2008). Yebei and his colleagues in their study suggest that PLWA may suffer enacted stigma, which can be manifested through avoidant behaviour.

To understand further, Goffman's conceptualised definition of stigma offers us a wider view and understanding of the dimensions it can take (Goffman, 1963). Stigma occurs when negative meanings are attached to discrediting traits such as HIV/AIDS, resulting in avoidance, less than full acceptance, and discrimination of people with

that trait. Holzemer and his colleagues further described three types of stigma: received, internal and associated (Holzemer *et al.*, 2006). In their study, received stigma includes neglecting, fearing, contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping, while internal stigma is thoughts and behaviours stemming from a person's own negative perceptions about themselves. The study further reported that enacted stigma²³ was primarily experienced as interpersonal discrimination and many of these experiences were highlighted as fear of contagion. This fear set the pace in which people were uncomfortable with contact with material objects, such as glass or utensils that were used or owned by a person with HIV. As a result of felt stigma,²⁴ PLWA who did not disclose found social support within their immediate family members but they were unable to rely on others who were outside of the family for full support.

In the study reported here, some participants who migrated to urban areas of Kampala reported hard times and more challenges. Participants in this category cited extended family as their source of support while in Kampala. Where their expectations of support were not met, some resolved to seek external assistance. Whilst the finding is supported by a previous study done in Uganda (Jackson *et al.*, 1999), the present study draws on cultural values of extended family systems which have historically provided a safety net during hard times, and many people with HIV/AIDS turn to it for support. However, in recent times, urbanisation and migration have weakened the extended family which remains the core provider of support and care for adults and children with HIV/AIDS (Jackson *et al.*, 1999).

²³ The process of stigmatisation culminates in enacted stigma: prejudicial attitudes and actual discriminatory behaviours such as interpersonal avoidance, verbal insults, and violence.

²⁴ Refers to the fear of being discriminated against.

5.6.5 Spiritual issues

Findings presented demonstrate that PLWA seek solace and support from religious faiths, which they reported helped them cope and live positively with AIDS. A growing body of literature suggests the apparent involvement of spirituality among PLWA (Byamugisha, 1998; Byrne, 1987; Chou *et al.*, 2004; Jackson *et al.*, 1999; Kylma *et al.*, 2009; Leana & Uys, 2003; Lyon, Townsend-Akpan & Thomson, 2001; Majumdar, 2004; Makoae *et al.*, 2008; Marshall, 1987; Merz, 1997; Parsons *et al.*, 2006; Philips, 2006; Swinton & Narayanasamy, 2002; Vance, 2006; Waliggo *et al.*, 2006; Watt *et al.*, 2009). The main focus of these studies suggests that a patient's spiritual beliefs may influence general wellbeing at the end-of life. Lyon and his colleagues suggest that religion has both positive and negative effects (Lyon, Townsend-Akpan & Thomson, 2001): on the one hand, positive in the sense that religion offers a positive mental attitude and emotional support using rituals to generate hope and comfort; and, on the other hand, negative in the sense that an individual can be excommunicated from church, or fear rejection or condemnation. This is particularly true with participants in the present study. Some participants felt condemned after the church failed to meet their psychosocial needs. It emerged that churches emphasise an HIV prevention message linked to immorality. Apart from such preventive messages which may stigmatise, pastors appear to be insensitive and failing to address issues related to living with HIV/AIDS. Thus, some PLWA end up more stigmatised and depressed, even in church, as happened in my study. The majority of participants who shared experiences in religious involvements concur with the findings of previous studies (Parsons *et al.*, 2006; Waliggo *et al.*, 2006; Watt *et al.*,

2009), however the present study cited the role of church and its members in supporting poor patients.

In contrast, Philips (2006) has reported how individuals perceive God and prayer to be essential to their intrinsic ability to cope. They also seek some support from church members with the hope that the church will play a more active role in reducing stigma through community teaching. This is true with findings of the present study, which showed that some participants got emotional, material and psychological support through counselling, prayers and church members' regular visits to their homes. The findings in this study demonstrate that, in as much as religious faiths provide PLWA with courage to face their conditions, it is also worrying that some believed that fervent prayers could lead to a cure for AIDS. Watt and his colleagues, for instance, have documented their concerns over what they termed as the impact of 'cure' messages in church on drop out from HAART (Watt *et al.*, 2009). In essence, it is unclear to what extent these 'cure' messages account for drop out in HAART. A Ugandan study (Wanyama, Castelnovo & Wandera, 2007) suggests that these 'cure' messages may play an important role in non-adherence to HAART, but it is under recognised. This is particularly true with some participants who dropped out of HAART in my study. Some engaged in prayers with the hope that they were already 'cured' and left off taking medication/HAART after only some few months to realise that their health had seriously deteriorated and they needed medical intervention. At this point, they were enrolled at HAU and into the study. Perhaps this notable finding is important to further explore the role of church messages on PLWA and its role in the HAART era. These findings reveal missed opportunities for religious

organisations to support PLWA, which needs to be further addressed in different religious settings.

From this study, it has been shown that undoubtedly many people turn to religion for spiritual support and answers in a world devastated by HIV/AIDS and many other developmental problems. This is supported by previous studies (Byamugisha, 1998; Jackson *et al.*, 1999). In Uganda, for instance, churches provide enormously beneficial home care services in rural areas. In addition, church congregations in Uganda give emotional, spiritual, and material support to people in times of crisis, including ill health and bereavement (Byamugisha, 1998). Other studies show religion as a self-care strategy to relieve HIV-related symptoms (Chou *et al.*, 2004). Further, in the HIV/AIDS era, where there is absence of a cure for AIDS, now most health care workers are reported to link their patients to spiritual care for hope for those who believe in life after death (Leana & Uys, 2003). The majority of participants in this study who belonged to religious faiths had better strategies of coping with HIV/AIDS. They lived positively and the connection with spirituality helped them to find the meaning of life and the trajectory of their illness. Whilst previous studies have also reported increased coping strategies amongst PLWA through immersing oneself in religion and getting more religious (Majumdar, 2004; Makoe *et al.*, 2008), the present study has shown that individuals have different religious expectations which need to be addressed.

5.6.6 Conclusion

Evidence in this study has demonstrated that there are many issues affecting PLWA. In view of participants' experiences, it is clear that there are many challenges which are context-dependent. While evidence suggests that experiences of PLWA have been shaped through the advent of HAART, there are challenges that now relate to living with HIV/AIDS in the post-HAART era. With HIV/AIDS as a chronic disease, there are several implications that the present study has attempted to capture. It is important to note that other studies have supported the key findings of the present study. The key findings of the present study relate to physical experiences, psychosocial challenges and the spiritual aspect among PLWA, and emphasise the paramount importance of understanding how models of African palliative care can be shaped to address these specific experiences and concerns. The role of HAU has also been illustrated in the context of its contribution to participants' lives. Overall, the study has revealed the fundamental challenge posed by poverty. In addition, this study found out that PLWA selectively disclose if anticipated rewards outweigh the perceived costs. However, it would be interesting if further study could be carried out to establish what determines the perceived costs and how that would influence disclosure. This study further reported experiences of patients on HAART treatment. However, with increased effectiveness of HAART and disease progression, the disclosure issue may be less clear. Therefore, it is important to study the various implications of living with HIV/AIDS which may take different dimensions.

The following chapter describes the results of measurements of palliative care outcome using the APCA African POS scale. It gives insight into the experiences of patients on a weekly basis for eight weeks.

CHAPTER SIX

MEASUREMENTS OF PALLIATIVE CARE OUTCOME USING APCA AFRICAN POS

6.1 INTRODUCTION

This chapter report findings of measurements of palliative care outcome using APCA African POS on PLWA. The participants were newly referred (self/hospital) to Hospice Africa Uganda and were followed up for a period of 8 weeks. Using a ten-item multidimensional tool (APCA African POS), the findings report important information on the 1st day (pre-intervention) and subsequent weeks of post-intervention.

This chapter begins with description of socio-demographic and clinical profile of participants followed by findings of 8-week period follow-up of patients using APCA African POS. In this chapter, I have reported experiences on palliative care measured as outcome trajectories over a period of 8 weeks and finally discussed at the end of the chapter. I have also given a brief conclusion with key summery findings. I will first begin to describe the participants.

6.2 SOCIAL DEMOGRAPHIC AND CLINICAL PROFILE OF PARTICIPANTS

Thirty patients were recruited for this study. The following table describes the socio-demographic and clinical characteristics of participants ‘

Table 6.1 Socio-demographic and clinical characteristics of participants

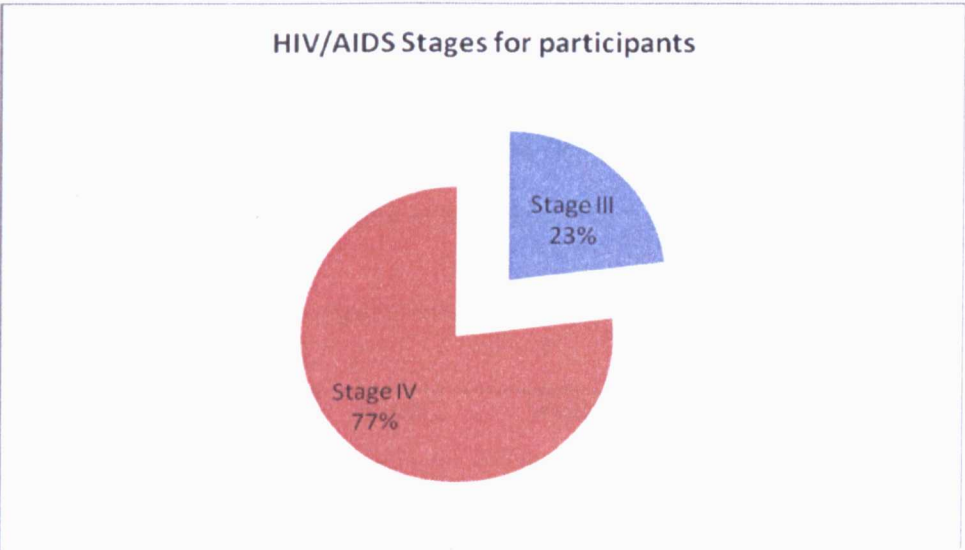
Demographic characteristics	N	%
Age		
<20	1	3.3
21-30	6	20
31-40	8	26.6
41-50	12	33.3
>51	3	10
Gender		
Male	16	56
Female	14	44
Marital status		
Never married/single	10	33.3
Married	14	46.6
Widowed	2	6.6
Divorced	2	6.6
Separated	2	6.6
Care setting of participant		
Home-care	17	56.6
Out-patient	4	13.3
In-patient	9	30
Residence status		
Urban	14	46.7
Semi-urban	8	26.7
Rural	8	26.6
Clinical characteristics		
Stage III	7	23.3
Stage IV	23	76.6
Presence of co-morbidity		
Yes	29	96.6
No	1	3.3
If yes		
HIV/AIDS related cancers	25	83.3
Opportunistic infections	4	13.3
Receiving HAART		
Yes	26	86.6
No	4	13.3

The average age for the participants was 36.3 years (SD±10.53). A total of 16 (56%) of participants were males and 14 (44%) were females. Whilst 14 participants

(46.7%) lived in urban setting, the rest came from Kampala environs. Nearly all participants (n=29, 96.6%) had co morbidities associated with opportunistic infections related to HIV/AIDS stage III/IV. AIDS defining cancers with opportunistic infections were major presenting distressing symptoms among participants.

The following chart illustrates the proportion of participant’s level of advanced AIDS.

Chart 6.1: Participants’ HIV/AIDS stage



Twenty six participants (86%) were receiving HAART treatment and just over three-quarters of the participants (n=23, 76.6%) were at stage IV-advanced AIDS.

6.3 BASELINE INFORMATION FOR PARTICIPANTS

This part of the chapter reports an overview of what can be described as baseline information regarding the participants during their first day of referral into palliative care. The 10-items/variables in APCA African POS tool was used to measure the outcome of care and how this changed over time. Therefore describing baseline information is paramount as it has implications on the rest of the findings. Thus, descriptive statistics has been used to describe sample recruited for the study at each time point. For instance, there were thirty participants

This number reduced over time due to the fact that some study participants died. Below table 6.2 shows the number of participants at each time period.

Table 6.2 Number of participants followed up

Time period	Week 1 (1 st day)	Week 2	Week 2	Week 3	Week 8
Participants	30	30	27	24	22

The following table describes the general mean scores at the first day of enrolment into the study.

Table 6.3 Base line scores using APCA African POS (when participants were 1st referred to palliative care).

Part A: Patient	1st week (baseline) N=30 Means
Q1. Please rate your pain (from 0 [no pain] to 5 [worst/overwhelming pain] during the last 3 days (<i>possible responses, 0[no pain] to 5[overwhelmingly]</i>))	3.33
Q2 Have any other symptoms (eg nausea, coughing or constipation) been affecting how you feel in the last 3 days? (<i>possible responses, 0 [no, not at all] to 5 [overwhelmingly]</i>)	2.83
Q3 Have you been feeling worried about your illness in the past 3 days? (<i>possible responses, 0 [no, not at all] to 5 [overwhelmingly]</i>)	3.59
Q4 Over the past 3 days, have you been able to share how you are feeling with your family or friends? (<i>possible responses: 0 [no, not at all] to 5[yes, I've talked freely]</i>)	1.73
Q5 Over the past 3 days, have you felt that life was worthwhile ? (<i>possible responses: 0 [no, not at all] to 5 [yes, all the time]</i>)	0.27
Q6 Over the past 3 days, have you felt at peace ? (<i>possible responses: 0[no, not at all] to 5 [yes, all the time]</i>)	0.17
Q7 Over the past 3 days, have you had enough help and advice for your family to plan for the future? (<i>possible responses: 0 [no, not at all] to 5 [as much as wanted]</i>)	1.00
Part B: Family member [carer]	
Q8 Over the past 3 days, how much information have you and your family been given? (<i>possible responses: 0 [no, not at all] to 5 [as much as I wanted]</i>)	1.73
Q9 Over the past 3 days, how confident has the family felt caring for the client? (<i>possible responses: 0 [not at all], to 5 [very confident]</i>)	2.00
Q10 Has the family been feeling worried about the client over the last 3 days? (<i>possible responses: 0 [not at all] to 5 [severe worry]</i>)	2.93

All participants during their first referral to palliative care at HAU had varied range of pain. It is significant to note that at this point, all the study participants had not received any intervention from Hospice Africa Uganda. This baseline data report findings of participants on the first day at HAU. Almost all participants ($n=28$, 93.3%) had more than moderate level of pain with almost half having severe and overwhelming pain ($n=14$, 46.7%). Only 8 (26.7%) participants had less severe pain, while only 2 (6.7%) had slight pain or body ache. The mean range for pain at first referral to HAU was 3.33 ($SD\pm 1.179$, $n=30$) in a scale of 5.

The study reported that almost three-quarter of participants experienced severe to overwhelming symptoms distress amongst advanced AIDS patients on their 1st day ($n=21$, 70%). The symptoms distress gradually decreased from the mean of 2.8 in the first week to mean of 2.09 by the end of 8th week. The study further reported that over three-quarter of participants were either with anxiety most of the time or pre-occupied with anxiety at their first day of encounter at HAU. The average participant's level of anxiety was 3.59 (*out of possible 5*, $SD\pm 1.042$, $N=30$) on 1st day before intervention.

Regarding level of sharing the information on their illness with friends or family members, the study reported the average level of 1.73 ($SD\pm 1.202$, $N=30$) in a scale of 5. While participants ($n=16$, 53.3%) reported that they sometimes or occasionally shared information with others regarding their illness/treatment, some participants ($n=4$, 13.3%) reported not having shared with anyone.

Of the total participants, just over half ($n=16$, 53.3%) experienced lack of peace on their 1st day of enrolment into palliative care. At baseline, participants' feeling of peace was on average 0.17 ($SD\pm 0.461$, $N=30$). On the views on participant's feelings on whether life was worthwhile, half of the participants (15, 50%) reported occasional

or a little feelings on worthwhile living on their 1st day as they enrolled into palliative care at HAU. The mean averages of participants' feelings on life as worthwhile living on the 1st day of palliative care was 0.27 ($SD \pm 0.74$, $n=30$).

In the aspect of accessing support, the study reported that all participants had inadequate support and advice at the time of starting palliative care ($n=30$, 100%, $\bar{x} = 1.00$, $SD \pm 0.871$). It is worth noting that some participants ($n=11$, 36.5%) had never accessed support and advice before enrolling for palliative care at HAU.

As for level of information, the study reported that almost all participants ($n=29$, 96.7%) had either inadequate or lack of enough information relating to their illness and treatment/care on the first day into palliative care. The mean average levels of information amongst participants on their 1st day was 1.73 ($SD \pm 0.828$, $N=30$). The study reported that while 19 (63.4%) participants received information, they still would have liked more or was hard to understand.

About two-third of care givers or family members ($n=20$, 66.7%) felt that they were either less confident or rendered their care with doubts/uncertainties at the first day when patient enrolled into palliative care. The study reported levels of confidence of family members on the first day of enrolment as $\bar{x} = 2.00$, $SD \pm 0.947$, $n=25$.

The study reported that majority of family members ($n=21$, 84%), were worried most of the time or preoccupied with worry. The mean average for family anxiety is 2.93 (in 0-5 scale). It is worth noting that there was no family member who was not worried and anxious in the first day, In conclusion baseline data on the 1st day (pre-intervention) which were significant are:

- There was high pain level experiences (on mean average score of 3.33)

- There was high patient's anxiety or worry (mean average score 3.59).
- Family's anxiety or worry was also reported high (on average mean score of 2.93).
- Patient's feelings about life's worthwhile and feeling at peace (on mean average score of less than 0.5).
- It is also reported that level of help or advice was very low (mean average of 1.00) at the baseline.

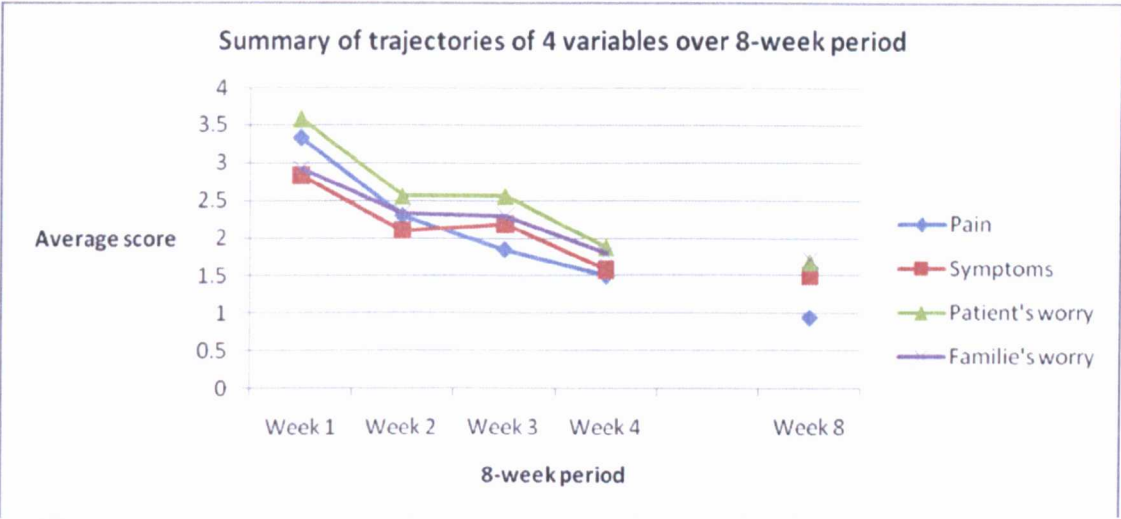
6.4 FINDINGS OF THE 8-WEEK FOLLOW UP STUDY USING APCA AFRICAN POS: TRAJECTORIES

Findings of the 8th week trajectories of study participants were measured using APCA African POS tool. To facilitate interpretation of the tool used, items have been grouped according to similar direction they assume while defining improvement scores. To understand the usage of APCA African POS I have described with illustration of graphs. To begin with, I used graph 6.1 which has four variables on 0 to 5 scale where 5 is worst and towards 0 is good. The four items which used this scale and the questions they relate to are:

1. pain (Q1),
2. patient's symptoms(Q2),
3. patient's anxiety (Q3) and
4. families' anxiety (Q10).

The trend of the curve decreases from left to right to mean improvement. The following graph shows the trend.

Graph 6.1 Summary of four items measured over 8 week period

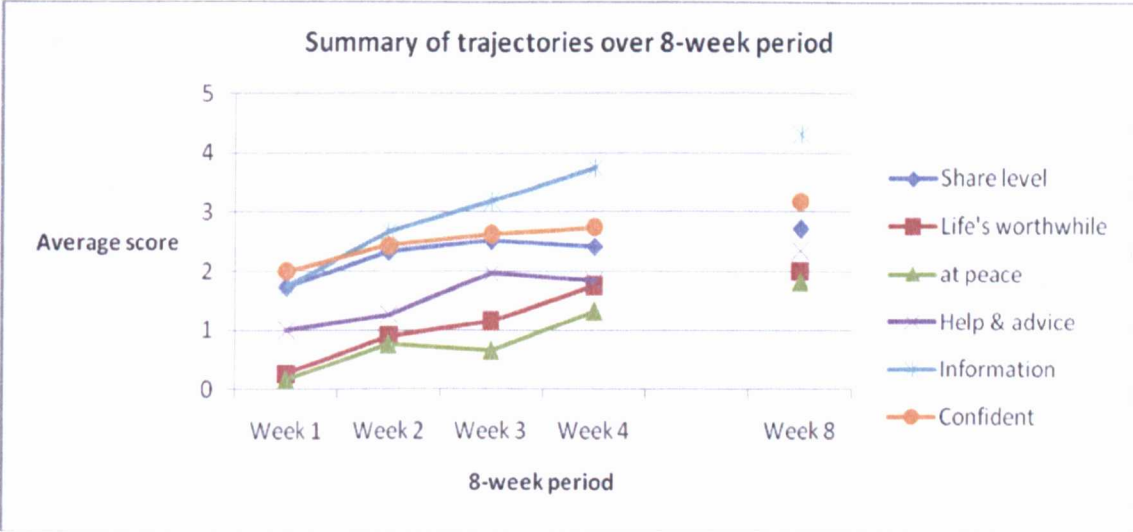


The most improved item as observed in graph 6.1 is pain while patient’s worry had slow improvement over time. The following graph describes the summary of six items measured over 8-week period.

Graph 6.2 describes six variables which used 0 to 5 scale where 5 is good or signifies improvement and 0 is worst. The six items measured under this scale and the questions they relate to are:

1. patients level of sharing (Q4),
2. patients feelings about life’s worthwhile(Q5)
3. feelings at peace(Q6)
4. access to support and advice(Q7)
5. Information given (Q8)
6. level of confidence(Q9)

Graph 6.2 Summary of six items measured over a 8 week period



On observation, graph 6.2 shows that the most improved item is level of information given to participants while the least improved item is participant’s feeling at peace. The following table shows weekly mean averages of scores measured over 8-week period.

Table 6.4 Weekly mean of variables measured using APCA African POS over 8 weeks

	1 st week N=30	2 nd week N=30	3 rd week N=27	4 th week N=24	8 th week N=22	General Mean
Part A: Patient						
Q1. Please rate your pain (from 0 [no pain] to 5 [worst/overwhelming pain] during the last 3 days (<i>possible responses, 0[no pain] to 5[overwhelmingly]</i>))	3.33	2.30	1.85	1.50	0.95	2.08
Q2 Have any other symptoms (eg nausea, coughing or constipation) been affecting how you feel in the last 3 days? (<i>possible responses, 0 [no, not at all] to 5 [overwhelmingly]</i>)	2.83	2.10	2.19	1.58	1.50	2.09
Q3 Have you been feeling worried about your illness in the past 3 days? (<i>possible responses, 0 [no, not at all] to 5 [overwhelmingly]</i>)	3.59	2.56	2.56	1.88	1.68	2.54
Q4 Over the past 3 days, have you been able to share how you are feeling with your family or friends? (<i>possible responses: 0 [no, not at all] to 5 [yes, I've talked freely]</i>)	1.73	2.33	2.52	2.42	2.73	2.32
Q5 Over the past 3 days, have you felt that life was worthwhile ? (<i>possible responses: 0 [no, not at all] to 5 [yes, all the time]</i>)	0.27	0.90	1.15	1.75	2.00	1.14
Q6 Over the past 3 days, have you felt at peace ? With possible responses 0 (not at all) to 5 (yes, definitely at all times)	0.17	0.77	0.67	1.33	1.82	0.89
Q7 Over the past 3 days, have you had enough help and advice for your family to plan for future? Possible responses: 0[no, not at all] to 5 [as much as wanted]	1.00	1.27	1.96	1.83	2.36	1.63
Part B: Family member (Carer)						
Q8 Over the past 3 days, how much information have you and your family been given? (<i>possible responses: 0 [no, not at all] to 5 [as much as I wanted]</i>)	1.73	2.67	3.19	3.75	4.31	3.03
Q9 Over the past 3 days, how confident has the family felt caring for the client? (<i>possible responses: 0 [not at all], to 5 [very confident]</i>)	2.00	2.43	2.63	2.75	3.18	2.56
Q10 Has the family been feeling worried about the client over the last 3 days? (<i>possible responses: 0 [not at all] to 5 [severe worry]</i>)	2.93	2.33	2.30	1.79	1.72	2.26

The following table shows the summary of all 10- item variables measured over a period of 8 weeks.

Table 6.5 Summary table showing the APCA POS findings for PLWA in 8-week study

	Week 1 (N=30) \bar{x}	Week 2 (N=30) \bar{x}	Week 3 (N=27) \bar{x}	Week 4 (N=24) \bar{x}	Week 8 (N=22) \bar{x}	χ^2 Chi- squared	Friedman's Test P values	General mean \bar{x}
Pain	3.33	2.30	1.85	1.50	0.96	21.496	0.001	2.08
Symptoms	2.83	2.10	2.19	1.58	1.50	38.67	0.0001	2.09
Patients worry	3.59	2.67	2.56	1.88	1.60	10.16	0.04	2.54
Share	1.73	2.33	2.53	2.42	2.73	43.670	0.01	2.32
Worthwhile	0.27	0.90	1.15	1.75	2.00	46.376	0.00	1.14
Peace	0.17	0.77	0.67	1.33	1.82	57.60	0.00	0.89
Help and advice	1.00	1.27	1.96	1.83	2.36	65.074	0.00	1.63
Information	1.73	2.67	3.19	3.75	4.31	83.970	0.00	3.03
Confident	2.00	2.43	2.63	2.75	3.18	55.24	0.15	2.56
Family's worry	2.93	2.33	2.30	1.79	1.72	4.075	0.073	2.26

Each item measured has been described below.

6.4.1 APCA African POS Trajectories

6.4.1.1 Pain trajectory

Q1. Please rate your **pain** (from 0 [no pain] to 5 [worst/overwhelming pain] during the last 3 days (*possible responses, 0[no pain] to 5[overwhelmingly]*)

In reference to table 6.5, baseline findings report 14 participants (46.7%), experienced severe or overwhelming pain in the first week but at the week 8, the number had dropped to 2 (9%). In the average pain levels of participants in this study were high during the enrolment, however, the pain levels reduced significantly over a period of time. Despite the significant reduction of pain amongst PLWA in the study over a period of 8 weeks, 9 (40.9%) still experienced moderate to less severely pain. Despite

study participants having enrolled into palliative care, by the end of the 8th week of study, there were non-existent pain free participants.

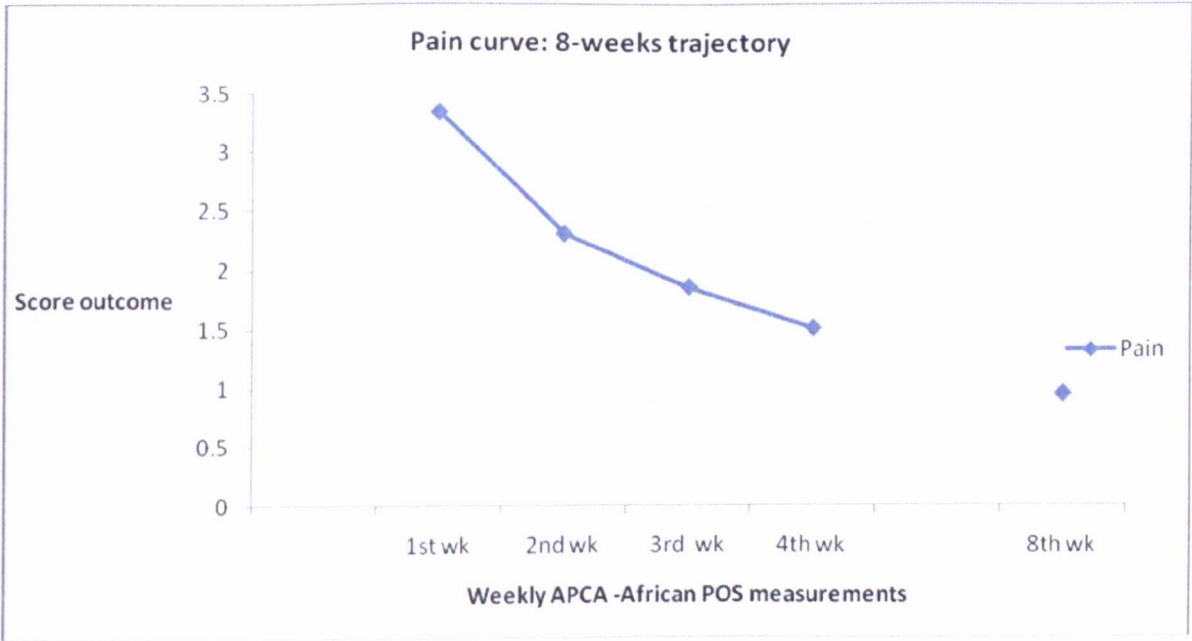
The following table describes the experiences of participants followed up for 8 weeks.

Table 6.5 Trend of pain as experienced by participants enrolled in the study.

Pain score	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	0	0	0	0	0	0	0	0	0	0
1. Slightly	2	6.7	6	20.0	2	7.4	4	16.7	11	50.0
2. Moderate	6	20.0	15	50.0	10	37.0	11	45.8	5	22.7
3. Less severely	8	26.7	5	16.7	10	37.0	5	28.8	4	18.2
4. Severely	8	26.7	2	6.7	3	11.2	3	12.5	1	4.5
5.Overwhelmingly	6	20.0	2	6.7	2	7.4	1	4.2	1	4.5

The graph below shows the trend of pain curve over a period of 8 weeks which shows increased pain at the enrolment times or period, however it declined with time.

Graph 6.3 shows the pain curve over a period of 8 weeks.



There was statistical decrease in pain over time, $\chi^2 (df\ 3)=21.496, p=0.001$. Inspection of median values in APCA African POS showed a decrease in pain of statistics from first week ($N=30, Md=3.33$), 2nd week ($N=30, Md=2.30$) and further decrease in the follow up week 8 ($N=22, Md=0.955$). Wilcoxon Signed Rank test revealed large change effect size ($r=0.501, z=-3.886, p=0.001$) among participants who were enrolled for a follow-up. This means that was relative large margin of difference between baseline pain score and post-intervention scores.

6.4.1.2 Symptoms trajectory

<p>Q2. Have any other symptoms (eg nausea, coughing or constipation) been affecting how you feel in the last 3 days? (<i>possible responses, 0 [no, not at all] to 5 [overwhelmingly]</i>)</p>

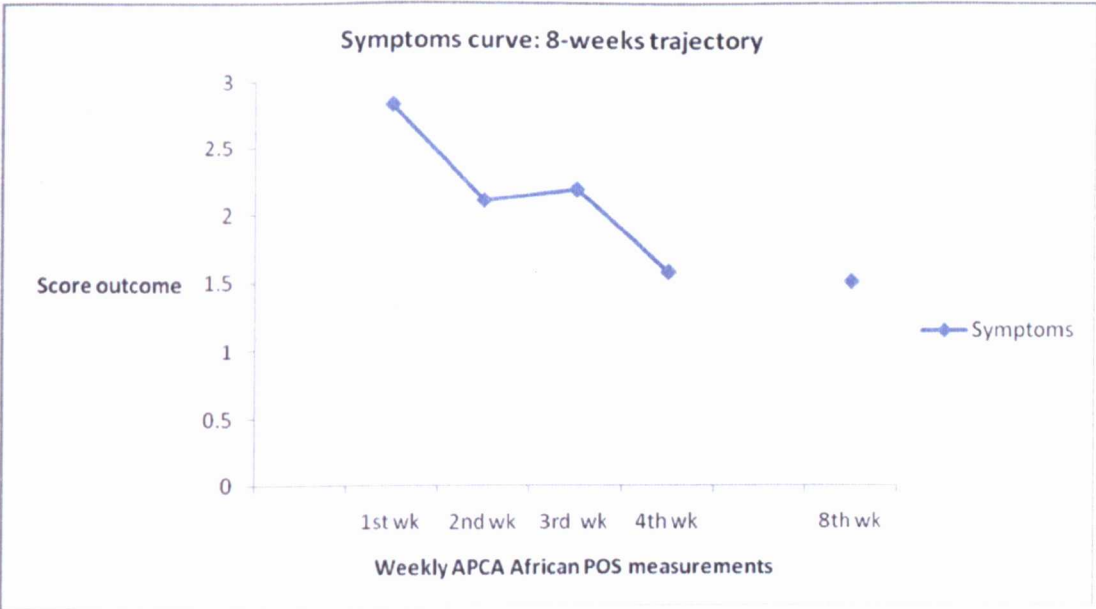
In reference to graph 6.3, findings on symptoms experiences amongst all participants in the study reported gradual decrease from week 1 (pre-intervention period) to week 8 (post-intervention). However, from table 6.6 shows that majority of participants ($n=21, 70\%$) had severe or unbearable and overwhelming symptoms distress on the first day of recruitment which gradually decreased. At the end of week 8, less than a third of participants ($n=7, 31.9\%$), experienced severe and overwhelming symptoms. On the 8th week, 14 (63.6%) participants only experienced moderate symptoms. The following table describes the varied symptoms experiences of patients followed up for a period of 8 weeks.

Table 6.6 Symptoms experiences by patients on their 8 weeks follow up.

Symptoms	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0 Not at all	0	0	0	0	0	0	0	0	0	0
1 Slightly	1	3.3	7	23.3	2	7.4	13	54.2	1	4.5
2 Moderately	8	26.7	14	100	7	25.9	8	33.3	14	63.9
3 Severely	16	53.3	8	26.7	10	37.0	2	8.3	2	9.0
4 Unbearable	3	10	0	0	5	18.5	1	4.2	5	22.7
5 Overwhelming	2	6.7	1	3.3	3	11.1	0	0	0	0

The following graph shows the symptoms curve over a period of 8 weeks. It shows that symptoms were improved in the 8th week and got worse towards 1st week.

Graph 6.4 Symptoms curve over a period of 8 weeks



Wilcoxon Signed Rank test revealed significant decrease in symptoms of participants enrolled for the study only for the first week of post-intervention ($z=-3.704$, $p=.001$)

with effect size ($r=0.302$) indicating a medium-level effect of time aspect on symptoms (using Cohen, 1988 criteria). There was a decrease in scores measured for symptoms experiences from week 1 where 16 (53.3%) participants experienced severe symptoms to 2 (9%) by end of the 8th week. The weekly median symptoms score for participants for week 1 (pre-intervention) $Md=2.833$, $N=30$, week 4 ($Md=1.58$, $N=24$) and finally 8th week ($Md=2.09$, $N=22$).

6.4.1.3 Patient’s anxiety trajectory

Q3. Have you been feeling **worried** about your illness in the past 3 days? (*possible responses, 0 [no, not at all] to 5 [overwhelmingly]*)

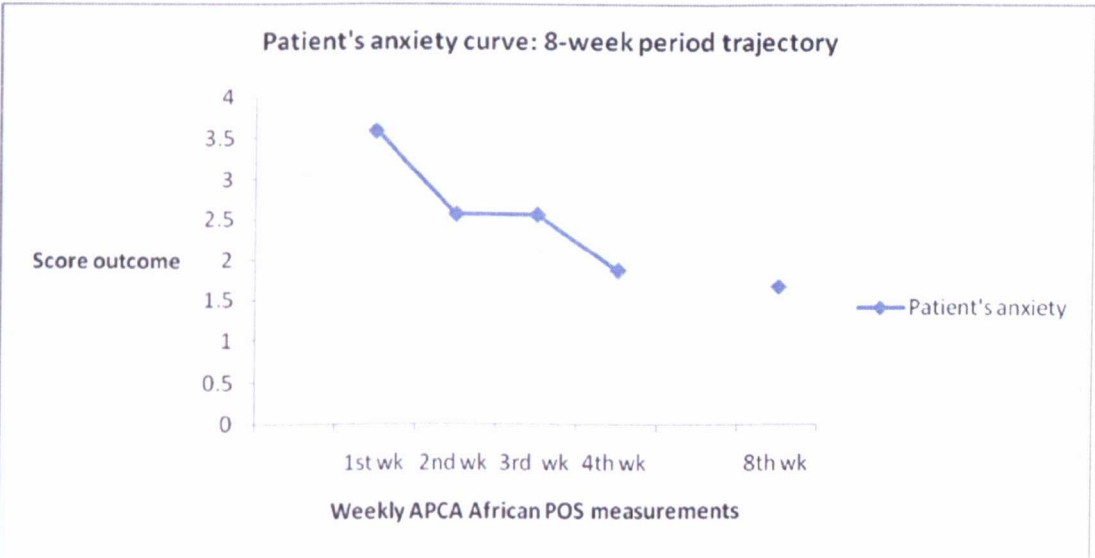
In reference to table 6.7, baseline findings report that 26 (86.7%) experienced anxiety over their illness most of the time or always pre-occupied and overwhelmed with worry. However, at the end of 8th week, the proportion of participants dropped to just over a half ($n=12$, 54.6%). The following table describes patient’s anxiety trajectory. The following table describes the patient’s anxiety trajectory over a 8-week period.

Table 6.7 Patients’ anxiety trajectory over a period of 8 weeks

Patient’s anxiety	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	0	0	0	0	0	0	0	0	0	0
1. Occasionally	1	3.3	3	10	7	25.9	2	8.3	3	13.6
2. Sometimes	3	10	8	26.7	6	22.2	8	33.3	7	31.8
3. Most of the time	20	66.7	18	60	12	44.4	14	58.3	10	45.5
4. always preoccupied	3	10	1	3.3	2	7.4	0	0	2	9.1
5. Overwhelming worry	3	10	0	0	0	0	0	0	0	0

The following graph shows the patient’s worry or anxiety which improved over a period of 8 weeks.

Graph 6.5 Patient’s worry or anxiety over a period of 8 weeks



Wilcoxon Signed Rank test indicated that there is a statistically differences in patient’s anxiety during their first week only. The test revealed significant decrease in patient’s anxiety only for the first week following their enrolment into palliative care services ($p=0.001$, $z=-2.84$). Further, the results of analysis showed relatively small effect size ($r=0.23$) in the first week on patient’s anxiety with no statistical difference in the

subsequent weeks of follow up, $\chi^2 (df\ 4)=10.16, p=0.04$. Inspection of median values however showed decrease in level of patient’s anxiety from across five points. In the first week ($N=30, Md=3.59$) participants displayed either all-time preoccupied state of anxiety or had anxiety most of the time which reduced in week 2 ($N=30, Md=2.67$) where anxiety among participants was reported sometimes. Further decrease in anxiety was observed with participants with some experiencing anxiety occasionally in the 8th week ($N=22, Md=1.69$).

6.4.1.4 Share feelings with family and friends trajectory

Q4 Over the past 3 days, have you been able to share how you are feeling with your family or friends?
 (possible responses: 0 [no, not at all] to 5[yes, I've talked freely])

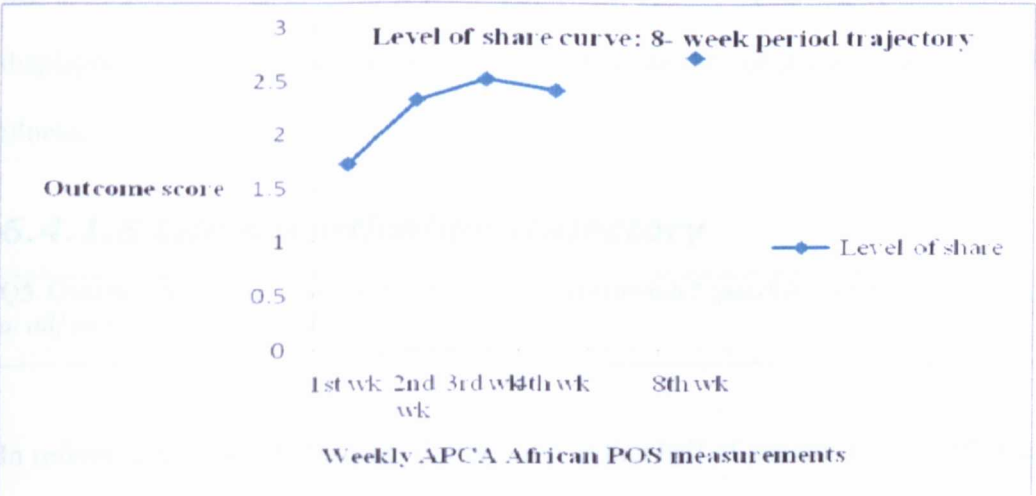
Referring to table 6.8, findings report that just over a half of participants ($n=16,53.3\%$) either did not want to share their feelings with family or friends or they did it was occasionally. However, by the end of 8th week, these participants had decreased to only 6 (27.3%). This means that participants had improved in their sharing level. For instance, table 6.8 shows that by the end of 8th week, 12 (44.5%) were able to share their feelings freely or most of the time. The following table describes share trajectory over a period of 8 weeks.

Table 6.8 Share feelings with family and friends trajectory of patients studied over a period of 8 weeks

Share level	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	4	13.3	3	10	1	3.7	1	4.2	0	0
1. Occasional	12	40	4	13.3	6	22.2	3	12.5	6	27.3
2. Sometimes	4	13.3	9	30	5	18.5	9	37.5	4	18.2
3. Most of the time	8	26.7	9	30	9	33.3	9	37.5	6	27.3
4. Yes, always	2	6.7	4	13.3	4	14.8	1	4.2	3	13.6
5. Yes, all the time & free to ask	0	0	1	3.3	2	7.4	1	4.2	3	13.6

The following graph shows the level of sharing curve which shows improvement on sharing level though with some plateau in the 4th week.

Graph 6.6 Sharing feelings curve for the 8 week period



Even though it observed (through mean values) that participant’s level of sharing improved at the beginning, it slowed down from 3rd week with participants preferring not to share much in the 4th week.

The results of the Friedman Test indicated that there is a statistical significant increase in level of sharing with me the information about their illness across the 8 week follow up period in the study, $\chi^2 (df 4)=43.670, p=0.001$. Further test using Wilcoxon-Signed Rank Test revealed that after enrolling on the study, participants' level of openness significantly increased in the first 2 weeks, $z=-3.069, p=0.002$, with relatively medium effect size ($r=0.255$). There was no statistical differences on the level of openness to share information from the 3rd week through to 8th week ($p>0.005$). Inspection of median score in APCA African POS displayed increased in level of openness to share information regarding their illness from the 1st week ($Md=1.73, N=30$) where participants shared information occasionally through to the 3rd week ($Md=2.52 N=27$) where participant's level of openness slightly improved however it decreased in the fourth week ($Md=2.42, N=24$). By the end of the study in the 8th week ($Md=2.73, N=22$), participants had opened up however they did not displayed free-exchange of information with their families or friends regarding their illness.

6.4.1.5 Life’s worthwhile trajectory

Q5. Over the past 3 days, have you felt that life was worthwhile? (possible responses: 0 [no, not at all] to 5 [yes, all the time])

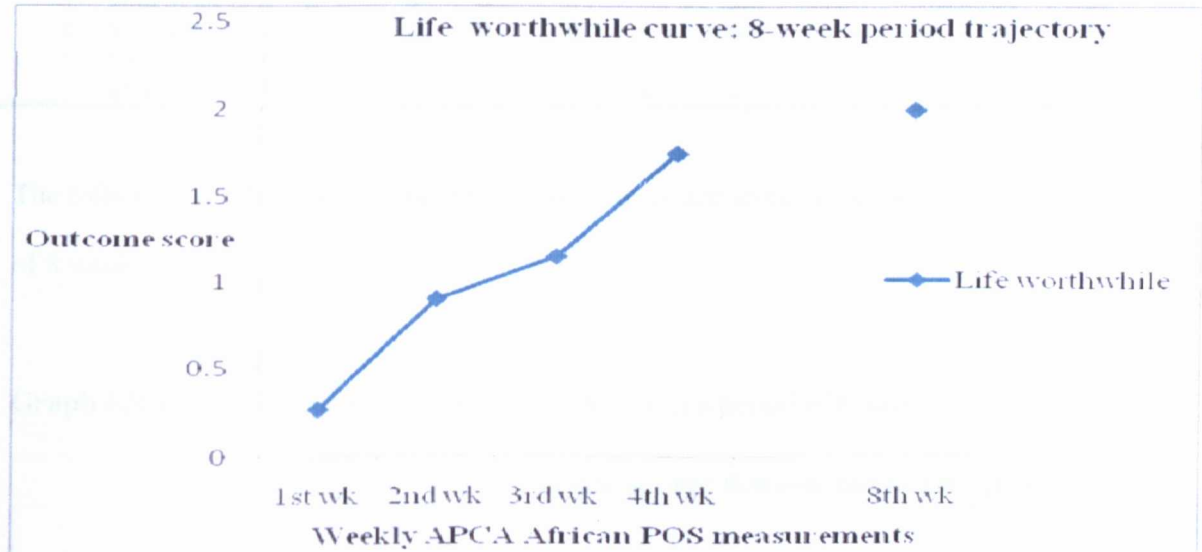
In reference to table 6.9, baseline findings report that half of patients (n=15, 50%) felt that life was a little worthwhile or occasionally worthwhile. However, this improved. By the end of 8th week, 10 (45.5%) participants felt life’s worthwhile most of the time with some perceiving life’s worthwhile sometimes. The following table describes the participants’ distribution in their views about perception of life’s worth over a period of 8 weeks.

Table 6.9 Statistics of all participants’ feelings of worth outcome

Life worthwhile scores	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	13	43.3	13	43.3	12	44.4	5	20.8	4	18.2
1. A little	12	40	11	36.7	6	22.2	3	12.5	4	18.2
2. Occasionally	3	10	2	6.7	2	7.4	11	45.8	4	18.2
3. Sometimes	1	6.7	4	13.3	7	25.9	3	12.5	8	36.4
4. Most of the time	0	3.3	0		0	0	2	8.3	2	9.1
5. Yes, all the time	0	0	0	0	0	0	0	0	0	0

The following graph shows the patient’s feelings on life as worthwhile as a curve over a period of 8 weeks.

Graph 6.7 Patient’s experience on sense of feeling life’s worthwhile over a period of 8 weeks.



Study reports significant improvement in the manner in which patients felt at peace with time from week 1 through to week 8, $\chi^2 (df, 4)=46.376, p=0.001$.

6.4.1.6 Patient’s feeling at peace trajectory

Q6. Over the past 3 days, have you felt at peace? With possible responses 0 (not at all) to 5 (yes, definitely at all times)

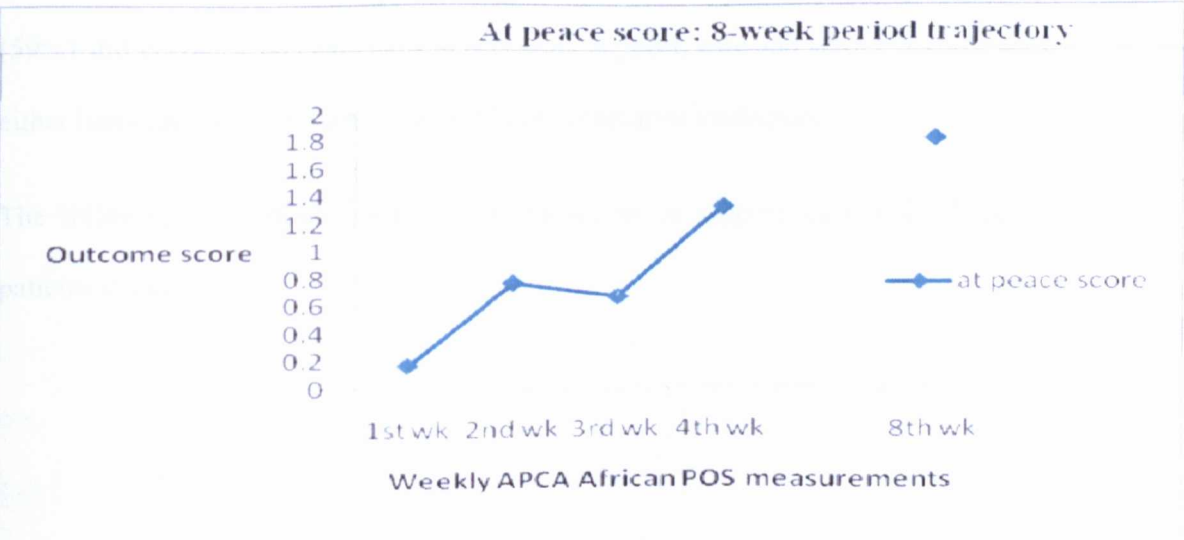
In reference to table 6.10, baseline findings report that just over a half of participants (n=16, 53.3%) reported not having felt at peace. However, the situation improved with time. By the end of 8th week, there were only 4 (18.2%) participant who still did not feel at peace. The following table describes the frequency of distribution of participant’s peace experience across the 8 weeks of the study. The following table describes the frequency of participant’s peace trajectory.

Table 6.10 Frequency of participants’ measure of feeling at peace outcome

Patient’s feelings at peace	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	16	53.3	14	46.7	14	51.9	5	20.8	4	18.2
1. Occasionally	13	43.3	9	30	10	37.0	10	41.7	1	4.5
2. Sometimes	1	3.3	7	23	2	7.4	5	20.8	12	54.5
3. Most of the time	0	0	0	0	1	3.7	4	16.7	5	22.7
4. Yes, all the time	0	0	0	0	0	0	0	0	0	0
5. Yes, definitely all times	0	0	0	0	0	0	0	0	0	0

The following graph shows the patient’s feelings on peace score curve over a period of 8 weeks.

Graph 6.8 Patient’s feelings on peace score curve over a period of 8 weeks.



Friedman’s test report a statistical significance improvement from week1 to week 8 in the area of feeling, $\chi^2(df,4)=57.60, p=0.001$. Wilcoxon Signed rank test revealed significance improvement at different points: between 1st & 2nd week, ($p=0.001, Z=-3.22$), between 3rd &4th week ($p=0.001, Z=-1.96$) and between 4th &8th week ($p=0.049$). There was no significant improvement between 2nd & 3rd week ($p=0.542$). Inspection of means of the score in week 1-8 reported the following: 0.167 (*week 1*), 0.767 (*week 2*), 1.20 (*week 3*), 2.267 (*week 4th*), 2.73 (*week 8th*).

6.4.1.7 Access to support, and advice trajectory

Q7. Over the past 3 days, have you had enough help and advice for your family to plan for future? Possible responses: 0[no, not at all] to 5 [as much as wanted]

Referring to table 6.11, the study findings show that at baseline, all participants experienced lack or inadequate form of support or access to advice. However, with time all participants were able to access some form of support and scores improved. By the end of 8th week, the findings shows that all participants had managed to get support or access to advice but at different levels. At week 8 however, 13 participants (59%) still encountered challenges in accessing support, care and advice because they either had support and advice occasionally or sometimes inadequate.

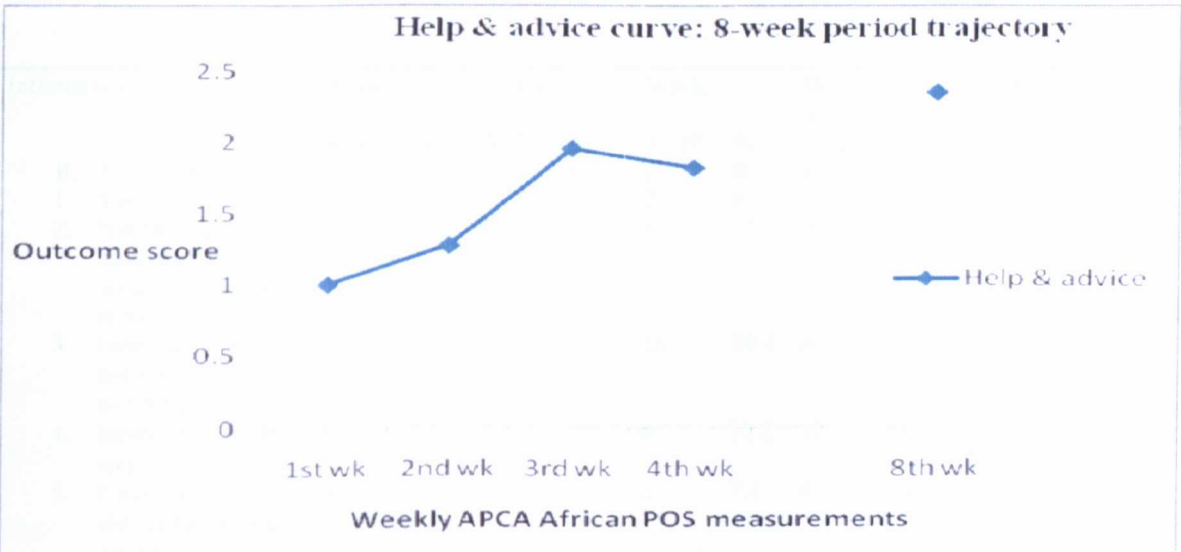
The following table describes the score on access to support, care and advice on patients studied

Table 6.11 Access to support, care and advice of patients studied.

Help and advice to plan for future scores		Week 1 N=30		Week 2 N=30		Week 3 N=27		Week 4 N=24		Week 8 N=22	
			%		%		%		%		%
0.	Not at all	11	36.5	6	20.0	2	7.3	2	8.3	0	0
1.	Yes, occasionally	8	26.7	11	36.7	5	18.5	6	25.0	3	13.6
2.	Sometimes	5	16.7	6	20.0	6	22.2	5	20.8	3	13.6
3.	Yes, but not adequate	6	20.0	6	20.0	9	33.3	6	25.0	7	31.8
4.	Yes, adequate	0	0	1	3.3	2	4.1	3	12.5	8	36.4
5.	Yes, as much as wanted	0	0	0	0	3	11.1	2	8.3	1	4.5

The following shows the patient’s experience of accessing support and advice over a period of 8 weeks.

Graph 6.9 Patient’s help and advice curve over a period of 8 weeks



Friedman’s test reveals significant increase in level of support and advice over time $\chi^2(df,4)=65.074, p=0.001$. Wilcoxon Signed rank test reported significant increase only between 2nd & 3rd ($p=0.001$) and 4th & 5th ($p=0.011$). Inspection of means for week one through to week 8 reported: 1.00 (*week 1*), 1.267 (*week 2*), 2.367 (*week 4*) and 3.333 (*week 8th*).

6.4.1.8 Information for patient and family trajectory

Q8. Over the past 3 days, how much information have you and your family been given? (possible responses: 0 [no, not at all] to 5 [as much as I wanted])

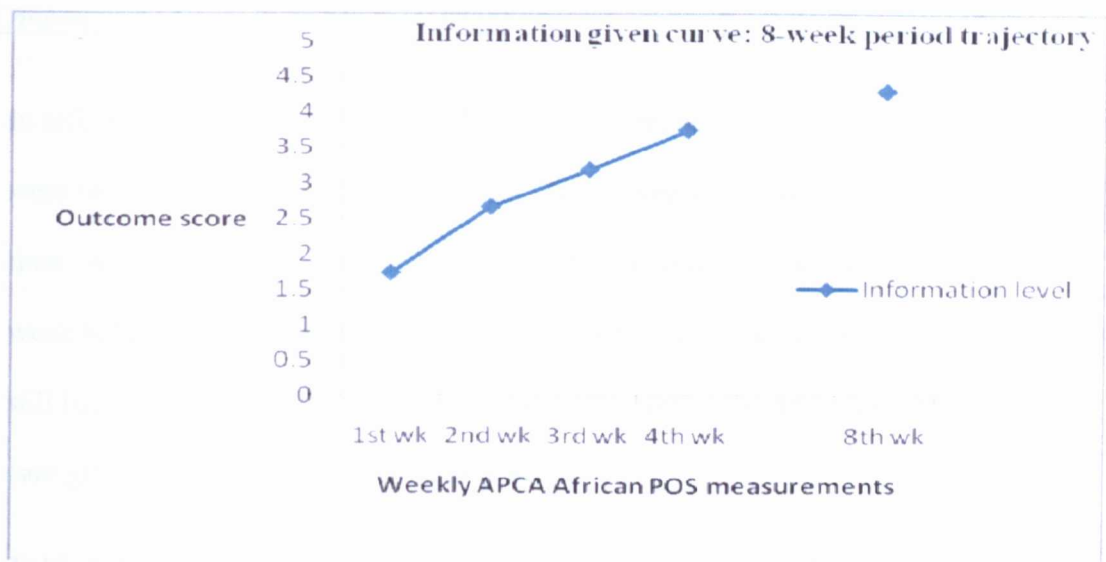
A total of 29 (90%) of participants (patients and family members) had inadequate information. However, at the end of 8 weeks there were only 3 individuals (13.6%) in the same category (inadequate information). At week 8, the rest of participants had either full information or understood the information related to illness, care, treatment and support except 2 participants who still found difficulties understanding the information given. The following table describes the levels of information received by participants over 8-week period.

Table 6.12 Participant’s level of information received over a period of 8 weeks

Information scores	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. None at all	2	6.7	0	0	0	0	0	0	0	0
1. Very little given	8	26.7	2	6.7	0	0	0	0	0	0
2. Information given on request but would have liked more	17	56.7	9	30	3	11.1	2	8.3	1	4.5
3. Information given but hard to understand	2	6.7	16	53.3	16	59.3	6	24	2	9.1
4. Information given and understood	1	3.3	3	10	6	22.2	12	50	13	59.1
5. Full information- always free to ask what I want and talked freely	0	0	0	0	2	7.4	4	16.7	6	27.3

The following graph shows the patient’s feelings on information given over the period of 8 weeks of study.

Graph 6.10 patient’s experience on information given over a period of 8 weeks



The results of the Friedman Test indicated that there is a statistical significant increase in overall information given to the participants across the first four points, in a 8 week follow-up study, $\chi^2 (df4)=83.970, p=0.001$. Further, Wilcoxon Signed Rank Test revealed significant increase in week 1-2, $z=-3.90, p=0.001$, with large size effect ($r=0.312$). The findings reported increased median score in the level of information. The first week reported the lowest levels of information ($Md=1.73$) where participants had little information or not adequate. The findings shows that it slightly increased with median score in 2nd week ($Md=2.67$) where level of information had slightly improved. Between 2nd and 3rd week there was further significant increase in level of information of participants, $z=-3.319, p=0.001$ with relatively medium effect size ($r=0.276$). During the second and third week, the level of information given had progressively improved to level of adequacy as observed in APCA African POS’ median score.

6.4.1.9 Family care giver's confidence trajectory

Q9. Over the past 3 days, how confident has the family felt caring for the client? (*possible responses: 0 [not at all], to 5 [very confident]*)

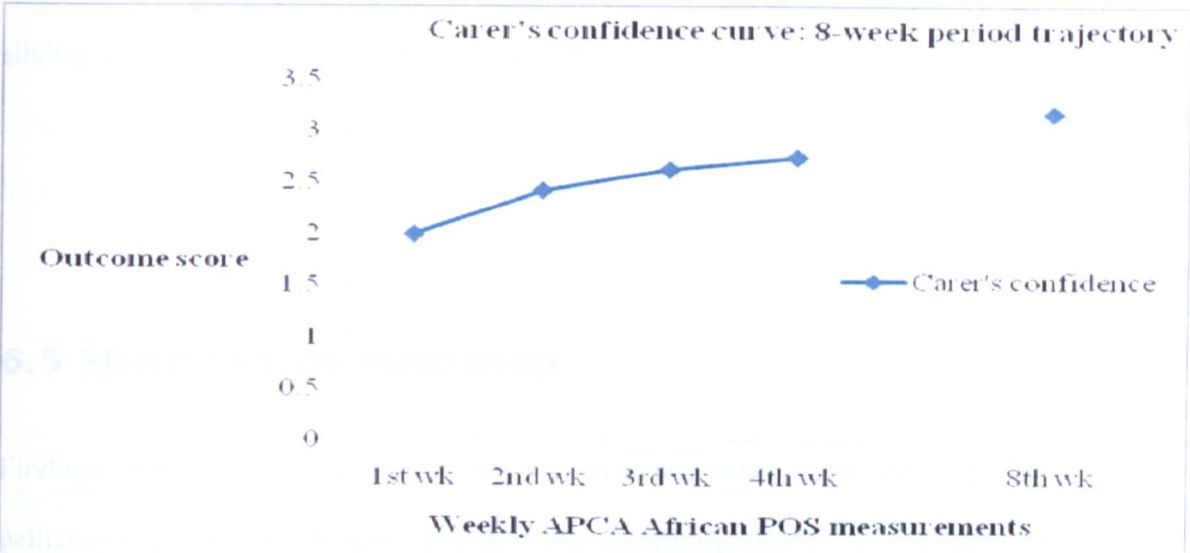
In reference to table 6.13, over two-third family members or care givers (n=21, 70%), were less confident with occasional doubt. These experiences however improved with time. At week 8, there were only few (4, 18.2%) who were still less confident. At week 8, half of family members had confidence however with few (n=5, 22.7%) who still had occasional doubts in their care giving. The following table describes family's care giver confidence over a period of 8 weeks.

Table 6.13 Level of confidence as scored by family care givers/relatives

Confident scores	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	1	3.3	0	0	1	3.7	0	0	0	0
1. Less confident	8	26.7	3	10	3	11.1	5	20.8	4	18.2
2. Sometimes in doubt/unsure	12	40	15	50	7	25.9	4	16.7	3	13.6
3. Confident with occasional doubt	7	23.3	8	26.7	8	25.9	6	25	5	22.7
4. Confident	2	6.7	4	13.3	7	3.7	8	33.3	7	31.8
5. Very confident	0	0	0		1	3.7	1	4.2	3	13.6

The following shows the family's experiences of confidence in caring for their patient over a period of 8 weeks.

Graph 6.11 shows the family member’s confidence curve over a period of 8 weeks.



6.4.1.10 Family anxiety trajectory

Q10. Has the family been feeling **worried** about the client over the last 3 days? (*possible responses: 0 [not at all] to 5 [severe worry]*)

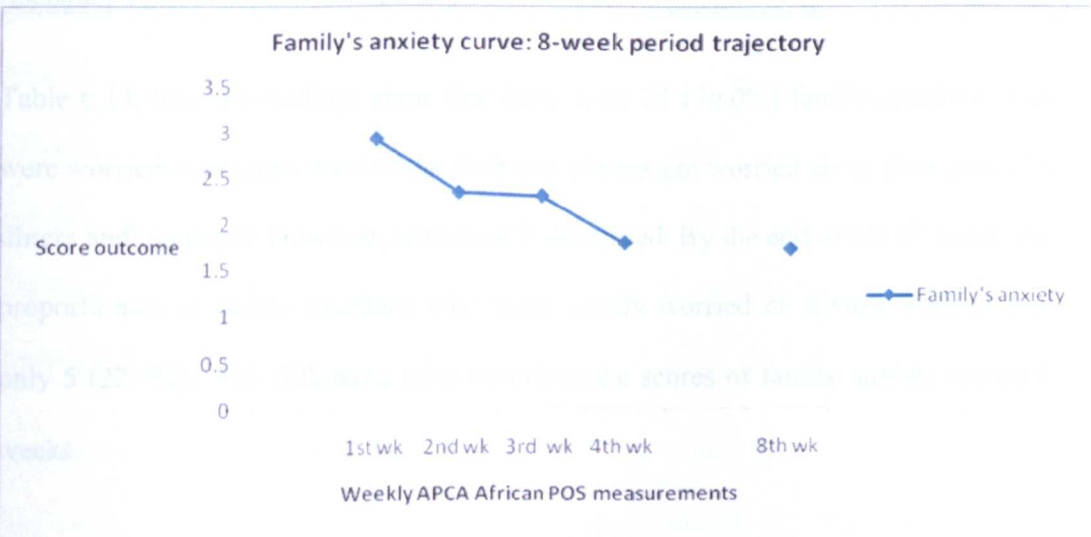
Table 6.14, baseline findings show that there were 21 (70.0%) family members who were worried or anxious most of the time and always got worried about their patient’s illness and treatment. However, with time it decreased. By the end of the 8th week, the proportionate of family members who were mostly worried or always worried was only 5 (22.7%). The following table describes the scores of family anxiety across 8 weeks.

Table 6.14 Family member’s anxiety levels and score of each week for the 8-week study

Family anxiety scores	Week 1		Week 2		Week 3		Week 4		Week 8	
	N=30	%	N=30	%	N=27	%	N=24	%	N=22	%
0. Not at all	0	0	0	0	1	3.7	3	12.5	4	18.2
1. Occasional	2	6.7	3	10	5	18.5	6	25	6	22.3
2. Sometimes	7	23.3	15	50	13	48.1	9	37.5	7	31.8
3. Most of the time	12	40	11	36.7	7	25.9	5	20.8	4	18.2
4. Yes, always pre occupied	8	26.7	1	3.3	1	3.7	1	4.2	1	4.5
5. Severe worry	1	3.3	0	0	0	0	0	0	0	0

The following graph shows the family’s worry or anxiety curve over a period of 8 weeks.

Graph 6.12 The family’s level of worry or anxiety curve over a period of 8 weeks



Using Friedman’s test revealed no statistical significant differences family anxiety across the 8 weeks, $\chi^2 (df\ 4) = 4.075, p > .005$). However analysis reported relative small size time effect ($r = 0.25$). Median score of APCA African POS revealed reduction in family anxiety from week 1 ($Md = 2.933, n = 30$) . Family experienced

anxiety most of the time in week 2 ($Md=2.33$, $n=27$) where family sometimes experienced anxiety. Subsequent weeks displayed family's anxiety has having reduced slightly as reported in week 8 ($Md=1.73$, $n=22$).

6.5 SUMMARY OF FINDINGS

Findings of this chapter reveal that there was an improvement in physical aspect of palliative care for example pain, symptoms distress management in the few weeks of palliative care: this can be observed in the graph 6.1. From observation (*please see graph 6.1*), the most improved item/variable was pain. On comparative terms, it means that patients responded to chemotherapeutic interventions (physical) faster than other areas such as psychosocial which took relatively slower pace. For instance, in graph 6.2 it is observed that there was an improvement in areas like patients and families' anxiety it was relatively slow. Further, by the end of the 8th week, the findings also reported that families were still more worried than patients. These findings as well have been supported statistically.

There are however some limitations and biases that might have been introduced in this study. It is worth acknowledging. For instance, due to the fact that almost all participants ($n=26$, 86.6%) were on treatment (HAART). There was also no comparison group (control group) and therefore it is certainly hard to ascertain how much of improvement (in the 10-items measured) is due to palliative care intervention. In reference to table 6.4, the use of mean averages to describe the trend of changes (improvement) from baseline data may not reflect a true picture. This is

because where we observe characteristic improvements, it may not totally be attributed to palliative care intervention but the average means may have masked the effect of eliminated 'worst scores' from critically ill patients who died during the study. The implications of this fact is that the trend of most graphs may look as though there are improvements but then it may be due to critically ill patients who died and graphs now look to have improved.

On a scale of 0 to 5 where 5 means worst and 0 means good, four items measure reflected positive improvement. The four items are pain, symptoms, patient's worry or anxiety, and family's worry or anxiety were high at the beginning (1st week) the decreased gradually over a period of 8 weeks.

On a scale of 0-5 where 5 means good and 0 is worst, six items measured showed improvement as seen in graph 6.2 where the improvement is observed to increase from 1st week to 8th week. The six items are level of sharing, patient's feelings of being at peace, level of information, family's confidence of taking care and patient's feelings on life's worthwhile. Using the score as a yardstick to measure the level of improvement or impact of care received, the findings report the greatest improvement in level of information from week 1 to week 8 with an average score of 3.03.

6.6 DISCUSSION OF EXPERIENCES OF PLWA AND THEIR CAREGIVERS IN UGANDA

The overall results from the study indicate that patients generally suffered from pain due to advanced AIDS stage. Pain, the most frequent and distressing symptom among PLWA in the present study is in line with six reports from Uganda (Cartledge *et al*, 2004; Jagwe & Merriman, 2007; Kikule, 2003; Logie, 2005; Logie & Harding, 2005; Stjernsward, 2002) and other eight reports from sub-Saharan Africa (Harding, 2004; Harding & Higginson, 2004; Harding *et al.*, 2003; Harding & Higginson, 2005; Stjernsward *et al.*, 2003; Selwyn, 2005; WHO, 2006; WHO, 2005). Whilst the present study builds the work of other authors who have undertaken palliative care studies among HIV/AIDS in other parts of the world (Borgo *et al.*, 2001; Breibart *et al.*, 1996; Hirschfeld 1998; Makoae *et al.*, 2005; Marcus *et al.*, 2000; Stephenson, 1996; Sukati *et al* 2005), the present study focuses on the experiences of AIDS patients and caregivers who started palliative care intervention and were followed up in their homes to establish their experiences.

Whilst Mokoae and his colleagues in their study documented high prevalence of pain in ambulatory patients with AIDS (Makoae *et al.*, 2005), the present study unveiled that pain amongst patients with advanced AIDS was always in the context of other distressing symptoms. Previous studies reported that experience of pain varied according to the stage of the disease (Makoae *et al.*, 2005), however, the present study give insight into experiences of pain among patients with advanced AIDS (stage III and IV) in different contexts of care setting. More particular contribution of the present study on how experiences of pain change over time which other studies reviewed lacked. The particular contribution of the present study was strengthening

understanding of experiences of living with HIV/AIDS and how palliative care needs change over time.

The study findings from this chapter reported high prevalence of symptom distress with majority of advanced AIDS patients experiencing overwhelming symptoms. Whilst similar findings have been reported in other studies (Collins & Harding, 2007; Joachim *et al.*, 2007; Makoae *et al.*, 2005; Voss *et al.*, 2007; Voss, 2005), it is important to note that the present study captured experiences of distressing symptoms over time. For instance, the findings of the present study show that experience of pain decreased gradually when PLWA started palliative care at Hospice Africa Uganda. Whilst the present study builds on the work of Jameson's study where he studied AIDS patients who were stage III & IV in South Africa, it did not focus on palliative care needs instead it concentrated on medical conditions of patients (Jameson 2008). Special contribution of the present study surrounds experiences of patients with AIDS with palliative care needs and how these experiences change over time.

The study findings from this chapter reported that the caregivers (family members) had some informational gaps and expressed lack of *confidence to take care of their relative*) at the start yet they were expected to give care for their relatives. Caregivers indicated in the qualitative interviews felt that they lacked information and support to boost their confidence. Caregivers mentioned that they faced challenges related to role of having to take care of their relative suffering from HIV/AIDS. Whilst studies undertaken in five different African countries (Uganda, Kenya, Botswana, South Africa and Malawi) also reported involvement of family members and community in care giving as well as unresolved caregiving burden (Harding *et al.*, 2009; Kipp *et al.*,

2007; McInerney, 2009; Ndaba-Mbata, 2000; Olenja 1999), the present study reported caregivers as not having considered caregiving as primarily a problem because their patients were close relatives. As a result, they supported and relentlessly cared for their relatives with compassion under all circumstances.

The study findings in this chapter reported high levels of anxiety and worry amongst both patients and their relatives (care givers) at the start which gradually decreased with time. At baseline, the high POS could be due to the fact that participants had not access form of care facilities, support and advice. In qualitative interviews, patients mentioned lack of support, access to care and medical care facilities including palliative care as among the main challenges. Further, qualitative interviews reported anxiety and level of worry heightened by stress related to changing roles in the family due to patient's bed-ridden state for instance supporting dependants (as breadwinner). Another area mentioned in qualitative interviews is HIV/AIDS stigma which heightens distress levels as well as emotional demands and frequently brings ambivalent experiences among care givers. Linked to this fact is the socio-economic impact of HIV/AIDS which disrupts social life and support: job-related factors such as having to stop working to take care, unemployment, adjusting to new roles as breadwinner, and lack of income-generating because of full-time care-giving complicated care giving environment. Fourth, is the fear and worry of contagion or contracting HIV/AIDS since relatives offered personal care with minimal hygienic measures for example use of gloves. Other studies have found that caregivers lacked knowledge about caregiving role and also availability of resources to support them (Alexander, 1994; Emanuel *et al.*, 2008; Kipp *et al.*, 2007; Orner, 2006). The present study has, however, added a new dimension of psychological aspect of caregiving:

fear and worry of contracting HIV due to prevailing circumstances under which caregivers operate in Uganda.

In the present study, it is believed that several psychosocial issues at individual, family and community may have a role in one's ability to disclose or talk freely about their health status. These findings have built on findings of other studies (Broun, 1999; Greeff *et al.*, 2008; Makoe *et al.*, 2008 Varas-Diaz, 2008) which suggest that psychosocial issues affect disclosure. Following enrolment into the palliative care intervention program, the study shows improvement in sharing, ability that may be attributed to the level of support achieved over time.

In conclusion, from discussion it is evident that palliative care interventions do have an impact on experiences of PLWA. Based on the 10-item APCA African POS, experiences of palliative care by PLWA differed between patients due to several factors including sampled population (in urban). It would be interesting to find out experiences of palliative care amongst PLWA in rural areas to check the differences.

The following chapter describes the experiences of health care staff in responding to the needs of PLWA studied. In this chapter, it gives insight into palliative care practices and challenges encountered in implementing palliative care in Uganda. In addition, key stakeholders describes current situation of palliative care in Uganda and views on how to improve coverage.

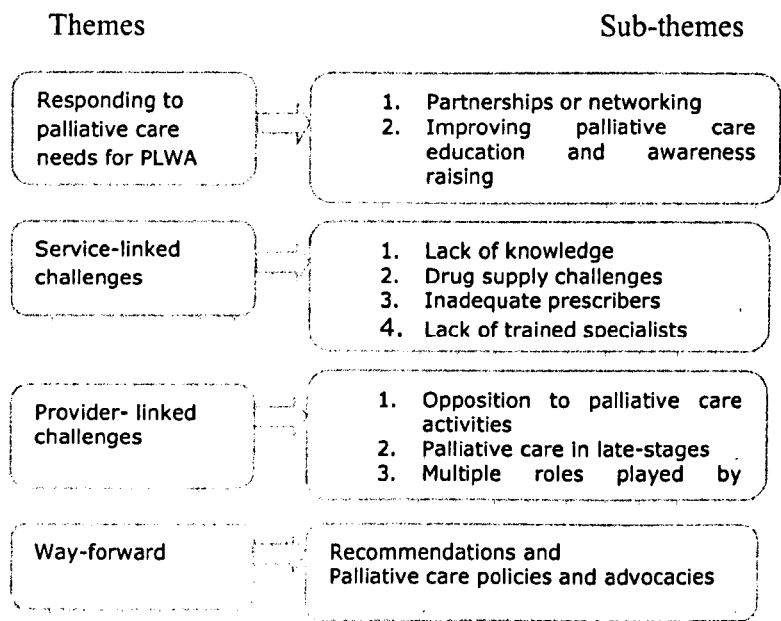
CHAPTER SEVEN

PALLIATIVE CARE SERVICES IN UGANDA: STAFF AND KEY STAKEHOLDERS' PERSPECTIVES

Introduction

The previous chapter details the experiences of living with HIV/AIDS and the experiences of palliative care receipt among PLWA and their care givers. This chapter examines how palliative care health professionals or staff (PCS) from Hospice Africa Uganda seek to respond to the needs or concerns of PLWA. It also reports the views of key opinion leaders involved in palliative care delivery in various capacities. The following figure 7.1 gives the themes and sub-themes reported in this chapter.

Figure 7.1: Major themes and sub-themes on palliative care staff and key opinion leaders’ view on palliative care activities.



I had two sets of interviews: first round of individual interviews and one focus group. There were 10 participants who participated in single interviews and 9 palliative health care professionals who participated in focus group. I conducted only one focus group discussion. Out of 10 participants who participated in single interviews, four participants also participated in focus group discussion conducted. Seven key opinion leaders were interviewed in the study.

In order to understand the nature of participants, I will begin with their brief background description. First, all health professionals²⁵ working in the area of palliative care were given opportunity to give their perspectives on palliative care delivery. These health professionals were linked to HAU and deliver palliative care services in hospitals (in-patient team), homes (home-visits/outreach/clinic) or at HAU

²⁵ Health care workers working in Kampala (hospital palliative care team or home visit team/outreach) and linked to HAU, mainly dealing with PLWA.

(out-patient palliative care services) to patients with HIV/AIDS and/or cancer and their families. In addition, they enable provision of palliative care services in Uganda, through advocacy, education and the training of stakeholders.

The health professionals' perspectives provide insight into how the HAU model of palliative care delivery to PLWA is implemented. HAU collaborates with a number of organizations and individuals to deliver palliative care services. These collaborations have enabled HAU to deliver services in areas that it otherwise would not be able to within its existing resource base.

The government of Uganda supports palliative care; this has been manifest in different ways, including most notably the provision of free morphine to all those who are in need. HAU has collaborated with the government in its endeavours to develop palliative care and enhance morphine availability by undertaking advocacy activities, providing, training, and participating in policy reviews. This activity has resulted in a law to allow nurses and clinical officers who undergo special training to prescribe morphine. Other policies which support integration of palliative care into health care systems include HSSP²⁶ designating palliative care, through the Ministry of Health, part of an 'Essential Clinical Care' health package available to all health facilities at all levels (MoH, 2005). As a result, palliative care services are gradually being made more available. However, the greatest barrier to palliative care expansion is the lack of prescribers or trained palliative care staff. In 2009, it was reported that there were only approximately 78 clinical palliative care course graduates (CPCC) serving the whole country and currently only 36 districts out of a total of 56 have at least one CPCC graduate offering palliative care services (Kiwanuka, Mayega & Downing, 2009).

²⁶ Health Sector Strategic Plan 2001-2006/2007-2011

This chapter therefore focuses on interviews of health professionals and opinion leaders in relation to three major areas: how palliative care staff respond to the palliative care needs of PLWA, the challenges they encounter in their service delivery and finally their recommendations for service development.

7.2 RESPONDING TO PALLIATIVE CARE NEEDS FOR PLWA: PERSPECTIVES OF HEALTH PROFESSIONALS

In this section I describe how, according to interviewees, palliative care staff seek to meet the needs of PLWA, across four dimensions:

1. Partnerships or networking together with stakeholders
2. Improving palliative care education and raising awareness of palliative care among communities and health care workers
3. Morphine availability
4. Advocacy and policies which support and strengthen initiation and expansion of palliative care services to PLWA.

7.2.1 Partnership

Health professionals reported that palliative care services to PLWA are delivered in the context of partnerships and networking with different agencies and individuals. For instance, interviewees mentioned that partnerships have been key to implementing the different models of palliative care at HAU. The first model is home based care. Many PLWA prefer home based care because they perceive that this reduces stigma and/or isolation. It is also easy way for family members to care and offer support because they do not have to travel extensively. There are usually home-visits from palliative care team who assess and review the patient periodically. The second model is in-patient care. In this model, hospital palliative care team do attend to the palliative care needs of the terminally ill patients with acute conditions. As soon as the patient is discharged from the hospital, hospital palliative care team prepare a discharge plan to link with community support network which includes palliative care staff and other health care worker. Third is the use of palliative care clinic. In this model, PLWA who need palliative care services but live long distances from the hospice, gain access palliative care support via an outreach clinic. Fourth are the road-side palliative care services. In this model, palliative care services are offered in a mobile clinic. The last model of care includes day care services directed at the provision of emotional and social support.

In five of the interviews with health professionals, reference was made to partnerships and networks established with key players, including: family members, social workers, community volunteers, local health care services and workers. Partnerships

extend into cancer care units as well as acute care units in hospitals and HIV/AIDS organizations. Partnerships are also established with Ministry of Health and other government bodies. For instance, one health professional described how HAU works closely with key agencies in various ways:

Yes, we do network with many, we do network with other healthcare units, NGOs, faith based, community based. As long as the help is going to be available to the patient, or to a particular community, we do network with all well wishers, whoever is willing to join us. And because HIV disease is not for an individual, it goes down to the whole community or village or district, there are many groups that come into play. So any group that is interested, we do network with them. But many of the AIDS organisations- TASO, Mildmay, and all faith based NGOs are almost in line with what we do, so we do network with them (PCS INTERVIEW 03)

Staff reported that when a patient is discharged from hospital, efforts are made to enable links with staff in the patient's locality in order to enable the continuation of palliative care support to them. One participant observed that HAU has complex networks at the level of districts which enable links with local health care staff, who can then support PLWA with palliative care needs. According to the interviewee, this strategy has the potential to serve those patients who live outside the HAU catchment area but many challenges remain in providing adequate palliative care services outside the catchment area, where access to care remains difficult:

If they're coming let's say from Jinja, we refer them to Jinja Hospice, if they are coming from Mbale, the same, but of course there are areas which do not have this service at all. And we encourage their health care providers, their primary health care providers to go and liaise with the teams, palliative health care teams in the nearest - sometimes it's quite far and unrealistic, but that's the situation, we try to utilise what we have. Whether they do go there or not, we do not know (PCS INTERVIEW 04).

In the focus group, HAU staff reported how they are interested to collaborate with other informal care givers like traditional healers or herbalists in order to respond palliative care needs of PLWA in the face of lack of access to other types of service:

Hospice does not violate other care they are getting, instead encourages them and helps them to bring out such issues so that we are able to work in collaboration. Even with traditional healers, it brings harmony, as long as we know that it is helpful to them (FGD).

In addition, staff reported in the group how they seek to aid the provision of palliative care services by collaboration with other agencies. Focus group participants underscored the role of community volunteers as having an important role in connecting the community with palliative care services:

I think palliative care is provided from the multidisciplinary team, because all aspects need to be covered whether it's physical, social and any other aspects. So you find that they will all have to be captured by different team members, different disciplines....you know even the community here is involved, one we have to identify the patient and the community volunteer can identify a patient and we as hospice staff can go in through the community volunteer (FGD)

Similar views were expressed in interviews. According to the staff interviewed, HAU collaborate with community volunteers who not only identify the patients in their respective communities but also refer them to palliative care services. According to the interviewees, community volunteers are very instrumental in community based services and receive training from HAU to function effectively. Part of the volunteers' collaborative role is to give feedback about the progress of patients, which interviewees considered useful in palliative care delivery:

We have some community volunteer workers, and there's a community volunteer coordinator, so that one coordinates the community volunteers in case there are any

patients in their community, the community volunteers usually give us the feedback on how the patients are doing. And they also refer patients to us from within their communities. Hospice usually trains them (PCS INTERVIEW 06)

7.2.2 Palliative care education.

Staff participants reported the significant role of palliative care education in responding to palliative care needs of PLWA and described on going palliative care education activities at different capacities and levels: for both health and non-health professionals. According to the palliative care staff, palliative care education has taken two dimensions: training of health care staff in palliative care and public education on palliative care to increase awareness and acceptability of palliative care. Further, staff reported that palliative care education has also targeted key leaders and health management teams to enable understanding of palliative care activities. Staff who took part in the focus group reported that they expected that they hoped that as a result of this education there would be less resistance and more support from key leaders and fellow health care workers:

Hospice provides training, the education department leads such that these people understand and also they are empowered to practice palliative care so that they will come to understand the important of palliative care or that collaborative aspect.... The issue is communicating as well as providing the holistic care. So they come to clearly know the difference between palliative care and other aspects they have got before (FGD).

Focus group participants further reported that providing training to nurses from various districts so that they could provide palliative care services has been a strategic

way to respond to palliative care needs of PLWA by making palliative care services more accessible:

I think one of the ways in which we have responded is by training nurses from various districts to be able to provide palliative care services; the clinical CPC nurses. Because they come from different districts that are much further, and you find that when patients come to hospice and they are assessed and are from another area or outside the catchment's area, then we look for some of these people who have received the training and can prescribe morphine, and we refer the patients to those specific individuals so they are able to get still the palliative care (FGD).

Four staff particularly emphasised in their interviews that palliative care training would increase capacity of health care workers, in the context of the introduction of palliative care in medical and nursing schools and its incorporation into the curriculum for both nursing and medical students:

Of recent, palliative care has been incorporated into their curriculum, and they need to have that information in order to be able to pass it on to the students. So we teach them the skills of how they can teach palliative care to their students.... at the moment it is the nursing students who are been taught, but the curriculum is also incorporated in the clinical officers' school. Yes, the doctors already. Before we went to the nurses, we started off with the medical students and - at first we were targeting those in Year 4 but of recent we have started targeting the 5th year students (PCS INTERVIEW 01).

Five palliative care staff reported in their interviews that in addition to the 9-month course targeting health care staff who are preparing to be palliative care specialists, there are short courses or workshops that target all health care and non-health care professionals. According to the interviews, this latter group (non-health professionals) trained in area of palliative care can help in identification of patients needing palliative care services and referral to appropriate services:

The people we train are in two categories, the health professionals and the non-health professionals. We have people with their professions who are teachers, councillors, okay, bankers; you name it..., and non-health who is spiritual carers for different denominations. And then we have another group, the community volunteers.... So they help in identification of patients and refer them to hospice (PCS INTERVIEW 02)

In addition, interviewees reported that there are need-driven courses targeting different districts in Uganda. Some are scheduled annually while others are run on request from local institutions:

Every year we draw up a plan for our courses, and we train in different districts, and we train in different areas. And we also do ad hoc training whereby an institution can come and request our training for their staff. So the expansion is done as need driven or as a plan from the department at Hospice. So areas are selected, where to carry out the training (PCS INTERVIEW 01).

Some staff reported that plans were underway to group districts into clusters for the purposes of establishing palliative care operations to support expansion of services in those respective districts. In so doing, interviewees reported that coverage of palliative care services would expand through training and supporting health care staff. According to one interviewee, mapping of districts for training purposes and targeting HIV/AIDS organizations helps strengthen palliative care service delivery:

At the moment we are coming up with a new programme where we shall cluster districts, districts in the neighbourhood. Like three, four districts will be brought together. We identify health workers from those districts, bring them together, train them, give them their skills and monitor them for a shorter period until they're able to stand on their own. This cluster programme is inclined to addressing HIV/AIDS organisations in those districts (PCS INTERVIEW 01).

7.2.3 Drug availability

Six palliative care staff interviewed and the focus group participants mentioned that another way of responding to physical needs is through making free oral morphine available in health facilities. According to one interviewee, the government is committed and willing to support the acquisition of oral morphine. Interviewees reported that morphine is centrally stored in Uganda: at the Kampala main pharmacy at Mulago National Hospital. It is in this hospital that oral powder is reconstituted to make oral morphine and supplied to health facilities across the country upon request:

We run as a lucky country, the Government of Uganda, the Ministry of Health in particular, buys the oral morphine powder, and then it's mixed at the pharmacy in the main hospital Mulago. So the persons who need this oral morphine or the trained persons can easily access the drug through ordering for the drug from Mulago through the Ministry of Health. They do not buy the drug, it is just on request and they receive it (PCS INTERVIEW 03)

The question here is perhaps whether we have enough prescribers to prescribe. According to the latter interviewee, Uganda has passed a significance milestone by allowing nurses who undergo special training to prescribe morphine and thus improve drug availability to patients through accessing it freely after prescription:

Now the Government has also come in with giving free oral morphine to anybody who needs it, and that is tremendous. Then they have, this is the only country in the world where they have allowed nurses who are trained in palliative care to prescribe morphine. Now it's also in that they allow clinical officers to prescribe morphine who are trained with us.... (PCS INTERVIEW 10)

As part of supporting districts and health facilities to improve on drug procurement and supply, staff interviewed mentioned that HAU help them to procure first consignment in the early stages of initiating palliative care in a district. Staff

interviewed reported that HAU collaborates with districts and hospitals to keep to the standards required for morphine storage & sustenance of the flow of morphine. This observation on how to stock, order, procedures, record-keeping and storage of oral morphine was reported in one individual interview:

They usually get supported, and before we go in, since we want this programme to be owned by the district, we make sure the district knows the procedures of procuring morphine, class A drugs. Initially when we are going to any district we tend to help them procure the first consignment which we use in training, and thereafter they're able to get the procedure of how to get more supply (PCS INTERVIEW 01).

Regarding expanding the scope and coverage of morphine supply in various districts, one interviewee observed that HAU runs 'start-ups' programs in districts in order to propagate morphine use at district level and the team from HAU educate clinical staff on morphine importance, how to access it and how to prescribe it to patients. Similar observations were voiced by others. For instance, one interviewee mentioned that HAU helps to procure the drug in the early stages but afterwards it is sometimes expected that districts will take up the role:

Apart from training, they (HAU) also support them through the district, like the district health services, hospice for a start help avail the drugs that are needed now like oral morphine, and all the documentation is carried out by those units there... (PCS INTERVIEW 06).

Five staff talked about challenges of making morphine available to PLWA to several factors. First, they reported on a lack of prescribers, which have only increased by small margin of 3% which, according to the senior staff interviewed, did not make any much impact. The second factor they reported was a lack of understanding on palliative care concept; this included the presence of myths about oral morphine

among health care workers which contribute to low prescriptions and meant that prescribers limited the availability of oral morphine to patients. Respondents called for increases in of training sites in order to increase the numbers of prescribers and ultimately increase drug availability to patients:

It is available but only if they are prescribed by a recognised prescriber. Now we're short of prescribers, and we worked this out a long time ago.... if all the patients in need were getting prescriptions from a doctor, there would be 225 patients to each doctor in the country. Now that doctor has to do the maternity, obstetrics, the children, everything. No doctor can sit down and right down 225 prescriptions per week for each patient. It's not possible okay. So we said okay let's increase the prescriber. But you know, in the people we are training, we've only increased the prescribers by 3%, it's nothing (PCS INTERVIEW 10).

Drug supply was further affected the existence of misperceptions on use of morphine. The myth is still a challenge: the belief that morphine causes addiction or hastens death among some health professionals is perceived as a great barrier to implementation of palliative care delivery to PLWA. According to the interviews, it is reported that there are still suspicion regarding morphine use because of belief that it causes addiction:

And health care workers were even suspicious that, you know these people by introducing morphine they want us to get our people addicted to this (PCS INTERVIEW 10).

In addition, one staff member reported existence of misperceptions about the drug and concludes that there are a lot that needs to be done to improve on understanding and general knowledge or concept of palliative care:

We are still trying hard to procure this morphine, sometimes going extra length or, you know. But other patients in the country of course find it difficult accessing morphine. Let me represent them although now we're talking about Hospice Africa Uganda patients. It's not readily available. The doctors have a culture that morphine is dangerous and, you know, we still have a lot of work to do (PCS INTERVIEW 04).

7.2.4 Advocacy & policies

Seven opinion leaders described what they referred to as series of advocacy activities which have become key factors underpinning the success of policies on palliative care delivery in Uganda. In their interviews, they described how the government is committed to supporting and integrating palliative care into health care systems. Interviewees reported their perceptions that advocacy and lobbying have had a positive influence on the current palliative care delivery in Uganda. For instance, policies on palliative care have been included in HSSP²⁷:

*Ministry agreed to that in 1993, morphine became available, and it is the oral morphine, liquid morphine, which was first registered as a formulation in 1993, '94 during my tenure as Chairman of the National Drug Regulatory Board, which we had founded in 1994, yeah...I think... my participation there was advocacy for availability and for the incorporation of palliative care into HSSP, because I was chairman of the taskforce committee, which worked out the elements on palliative care, which had to be incorporated into the health policy, yeah **KI INTERVIEW 01**)*

Another story tracing the history of nurse prescribing in Uganda is well articulated in one interview where the participant described how series of lobby accounts gradually led to change of statutory laws in Uganda finally opened up opportunity for nurses to prescribe oral morphine. According to the interviewee, this led to one of the major milestones in development and strengthening of palliative care in Uganda:

We were going to the Ministry of Health and convinced them that look you have one doctor to 18,000 people, and there are areas where people have no access to a doctor, 50-70% of our population may never see a doctor at all. So we said the only people available at the most remote health units are medical assistants or nursing assistantsThey did a lot of consultation, including WHO, INCP and all those, and eventually the Government agreed having realized that they don't have enough personnel to prescribe this medicine. Yeah. So on 24th April 2004, a statutory instrument came out of the Ministry of Health which allowed that these people, so well trained, could

²⁷ Health Sector Strategic Plan 2000-2005/2006-2011

prescribe morphine, and as you know palliative care is carried out basically by nurses and supported by clinical officer(KI INTERVIEW 01)

Similar stories about how policies have gradually formed and grown to support palliative care activities were narrated by another staff. For example, one palliative care staff member described how morphine has been included in Essential HIV care kit²⁸ as a result of advocacy and lobbying which means that all HIV/AIDS organizations will now expand their mandate to having pain management in their services:

Through advocacy recently we've influenced the incorporation of a basic palliative care kit into the basic HIV care kit which has been designed by the national HIV body.....Lobby for basic palliative package that is in our simple ways, we just managed to lobby, to advocate that morphine be made part of the essential palliative care, of the essential HIV care kit (PCS INTERVIEW 04).

Interviewees reported a series of accounts of advocacy activities which led to policy reviews and expansion of palliative care services in health sectors/systems. Interviewees mentioned that their efforts can be observed in the recent development in which the Uganda AIDS Commission (UAC) has accepted the inclusion of a palliative care package in Essential HIV/AIDS kit throughout the country. This means that HIV/AIDS organizations in Uganda will now be propelled to offer new services which include palliative care. An example of such HIV/AIDS organizations includes HAART centres. Interviewees perceived that policies are under revision and lobbying is on-going:

There's been quite a lot of work in Uganda on getting palliative care into the national policies.....they're just revising the HSSP to have Version 3 out, and we've just suggested new wording which is a lot more comprehensive, which talks about the need

²⁸ Minimum requirement for all HIV/AIDS organization offering services to PLWA

for palliative care to be integrated into all aspects of the healthcare system available at community level, at hospital level, at specialist level (KI INTERVIEW 03)

One palliative care staff mentioned the need to link evidence to advocacy activities to convince policy makers, by making use of information from published research that has identified unmet palliative care needs, especially psychosocial issues:

Another important thing is of course research, the evidence based research we have been doing here at the Hospice Africa, research findings reveals some of the gaps, much as we've been providing that quality of care, it reveals for us some of the gaps, which gaps are improved or they're planned by the team jointly to cater for some of those gaps... the team revealed psychosocial issues as major concerns (PCS INTERVIEW 05).

Similar views were voiced by more others; some mentioned how palliative care association of Uganda (PCAU) is currently involved in developing an evidence base which can be used in advocacy work. Others reported the use of a survey to map out palliative care services to establish baseline data necessary to inform the next step of advocacy work:

It's trying to get baseline, PCAU is surveying a baseline data on services that are available and how far they are from the hospitals and from patients and which is the nearest palliative care service. So we hope that using that we shall strengthen the palliative care service providers, I mean provision (PCS INTERVIEW 04).

7.3 CHALLENGES OF PALLIATIVE CARE DELIVERY

Staff were asked about the obstacles they had encountered in delivering palliative care amongst PLWA in Uganda, reporting their perception that there are still several challenges and barriers to effective palliative care in Uganda. Several reasons were given, which can be categorized into either service-linked or provider-linked factors. Participants indicated that two categories broadly covered the challenges of palliative care delivery to PLWA in Uganda.

In one hand, service-linked challenges include

1. lack of knowledge about palliative care,
2. drug supply challenges,
3. inadequate prescribers
4. lack of trained specialists.

On the other hand, provider-linked challenges include:

1. opposition to palliative care activities,
2. palliative care in late-stages,
3. difficulties to follow-up patients,
4. socio-economic challenges

Service-linked challenges

7.3.1.1 Lack of conceptual understanding of palliative care

Six participants interviewed mentioned that there is lack of knowledge about palliative care as a concept, which in several ways has hindered palliative care provision to PLWA. One staff member mentioned how the relatively new discipline/concept has not been fully grasped and it is still under development:

The main challenge is really palliative care been relatively new. Some of the people don't grasp the real concept of what palliative care is..... So you find that it poses a challenge training people and not finding out what exactly they're implementing in their workplaces (PCS INTERVIEW 01).

One interviewee mentioned that some people in District health management team (DHMT) who are responsible for staff deployment, do not appreciate palliative care partly because of lack of understanding. Other interviewees reported a lack of support of newly trained staff. Some realized their bosses' pessimistic attitude towards palliative care practice as observed at their workplaces when people are being trained and then their new skills are underutilized in some cases since they are moved to other areas of care:

So somebody can do a nine month programme here, leave very good at what they do, they don't get the practice because they're put into maternity or somewhere where they don't need palliative care (PCS INTERVIEW 10).

One staff member interviewed reported lack of knowledge about the principles of palliative care. There seems to be misunderstanding about what exactly palliative care

means amongst health professionals. Interviewee mentioned that palliative care is still a unique discipline that has been developing and yet to be appreciated by others:

Yeah, I think the major problem of delaying availability of palliative care is lack of knowledge. When you ask about a hospice, people don't even know what a hospice is, they say is it a hospital....the principles of palliative care, are just beginning to get to the health professionals here. So it's a new specialty. It's an area which some of us have seen developing (PCS INTERVIEW 09)

In other instances, these misunderstandings of palliative care concept according to interviewee is attributed to some funding agencies for instance PEPFAR. Interviewee describes how these misunderstandings need to be corrected:

But the biggest problem we've had is that PEPFAR²⁹ have come in with a different definition of palliative care. And because they've come in with a different definition of palliative care, people in the AIDS sector, which has grown hugely since '93, do not understand what palliative care is. They think that support care of giving food and counselling people at the beginning is palliative care; that is not palliative care; that is support care (PCS INTERVIEW 10)

7.3.1.2 Drug supply challenges

Five individual interviews and focus group discussion with palliative care staff raised the issue of drug supply, identifying several challenges. These challenges range from international level, national level to grass-root level or final consumption/usage. Interviews reported that the process is so complex and bureaucratic that the process alone may cause delay of drug flow. In the views of five participants interviewed, there are common barriers to drug supply related to logistics at both national and

²⁹ The US President's Emergency Plan for AIDS Relief

district level. For instance, one staff mentioned reluctance among some district staff (in the health management team) to facilitate collection of morphine from central location based in Kampala:

The challenge is the availability. Some districts are not just vigilant about collecting like the morphine from the central location, like the National Medical Stores. But for some places like Jinja, you know, they take the morphine from hospice at Kampala (PCS INTERVIEW 06).

Further interviews revealed how complex and bureaucratic procurement of drug may delay drug supply flow as reported by one of the pharmacist. One interviewee reported that after an order is made, it is passed on to medical superintendent or head of unit in a hospital who is supposed to seek approval from district director of health services. After approval, the order sheet is then sent to Ministry of Health who scrutinize the order before assenting. Responsible office in Mulago National & Referral Hospital will then receive letter confirming that indeed all steps have been adhered to and that morphine could now be issued to the needy:

Now after making the order, then you will now pass the quantities of your order to the medical superintendent, or the head of the unit, who then will make attachment of the letter which is been addressed to the district director of health services, because all health centres in Uganda are under district director of health services as per that very district. Then later on after the approval of the district director of health service then it will be forwarded to the Ministry of Health who then will look upon the figure and make a survey and then they will analyse. Now when the approval comes that these people qualify, then they will be given accrediting letter which will be addressed to Mulago for the quantity of morphine which they are supposed to get, and later on they go and get them (PCS INTERVIEW 07).

These bureaucratic steps affect drug flow and make drug procurement and supply quite difficult. The patients who are in need of morphine may have to suffer for a while before they get morphine.

Two palliative care staff interviewed reported challenges related to packaging of drug. Interviewees mentioned that HAU, a non-government and charitable organization is not supported by the government and as result do encounter many challenges. Staff reported that the greatest challenge is related to inability to afford all steps of quality assurances in preparation and packaging of oral liquid morphine:

Then another challenge is Hospice being a charity organisation, actually we can't afford all the steps of quality measures in preparation of morphine... now packing materials we use recycled mineral water bottles (PCS INTERVIEW 07).

This excerpt displays lack of resources to ensure that drug packaging is standardized. As a result, compromised quality assurance may impact on general use and supply of morphine.

7.3.1.3 Inadequate number of morphine prescribers

Six palliative care staff interviewed reported that there are insufficient morphine prescribers and reported several reasons for this observation. First, that although HAU have palliative care specialists who prescribe morphine to all PLWA enrolled at HAU, their range is limited to approximately 20km from HAU. Interviewees reported that palliative care services outside HAU catchment area thus depend on the availability of prescribers at district hospitals or district levels.

We are implementing a strategy where palliative care is provided at all levels depending on the competency available.. ...We are also getting all the stakeholders to ensure that we have palliative care as an integral part of the National Health Service..... We have some challenges with the prescriber level at present.... So we have introduced a course which is run by Hospice, where nurses who have a Diploma in Palliative Care can be prescribers and practice palliative care independently (KI INTERVIEW 06).

Second, the numbers of doctors in Uganda are very few, relative to the many patients needing prescriptions. One frontline staff member called for more training to increase number of prescribers because the available doctors do everything meaning palliative care may not be given due attention:

Now that doctor has to do the maternity, obstetrics, the children, everything.... So we said okay let's increase the prescriber (PCS INTERVIEW 10).

Third, employers do not support the few trained staff in their respective workplaces, instead they are frequently transferred to remote areas where they are not able to keep in touch with palliative care network. Interviewees reported some of the challenges at workplaces which included poor retention of trained staff members:

Okay, the challenges are that they're few and the patients are very many, trained people are not kept in the same facilities for a longer period. You find that they've been trained, they're well equipped with the knowledge to practice palliative care but after a very short time they're transferred very far away where they're not in touch with the palliative care team in their given district (PCS INTERVIEW 01)

Even the few staff who are trained are not fully utilized in the hospitals. According to one interviewee, palliative care staff end up doing or practising palliative care as a side activity, outside hospital setting or in the homes as voluntary activity:

Some of them do palliative practice, palliative care as a side activity, or a voluntary activity but...So we have a problem of incorporating palliative care into the general running of the hospital. That's the major challenge we have, yeah (PCS INTERVIEW 09).

In addition to challenges mentioned above, other staff reported difficulties related to getting health care workers to be trained. One interviewee mentioned that hospital

managers are reluctant to send their staff for training and mentioned the need for government to encourage more staff to train and thereafter support them by employing trained staff to work health facilities as to as promote palliative care services:

One of the things they find difficult is getting people,if they keep sending these staff on regular basis, then they will be able to have palliative care strengthened within their hospitals. And this has to go down to the Ministry whereby they have to employ more people to these units, and avail them for training (PCS INTERVIEW 03).

Three participants mentioned that because there are inadequate number of prescribers available, they are overloaded especially in the public health units and hence lack time or have minimal time to practice or prescribe. According to one palliative care staff interviewed, several reasons contributed to this observation. One of the contributing factors is that there is only one institution which trains palliative care staff in Uganda and the capacity to train staff-prescribers is limited:

We've got to increase the sites that can train prescribers, at the moment it's only Hospice, but we need Mildmay and other places to take on trainee prescribers (PCS INTERVIEW 10).

In addition, another interviewee mentioned that there is an imbalance in number of prescribers and that this mirrors the wider imbalance in resources allocation. According to interviewee, rural areas may have limited number of prescribers because it does not attract as more prescribers as urban areas:

Okay. Of course there's a difference between urban settings and rural settings in Uganda. First and foremost, there is inequity, you know. There are fewer hospitals in rural areas, there are more hospitals, more health care providers, nurses, and doctors prefer to stay in the urban areas (PCS INTERVIEW 04)

7.3.1.4 Lack of specialists trained to offer palliative care services

Staff reported shortages of trained palliative care staff in the country. The focus group reported challenges on quality of care given as a result of minimal time spent with patients due to few palliative care specialists. In the focus group, it was further reported that there is usually a larger population of patients with palliative care needs and there are few staff. In the opinion of palliative care staff in the focus group, there is always limited time to address all patients' palliative care needs. As a result, the group reported that it may impact on their quality of care given:

Yeah, time is a problem to provide palliative care. With palliative care it would really mean giving all the patients holistic care. That is looking at the physical, psychological, social and the spiritual aspects. So even that at one moment that person or a team has more than three patients to see, the time limit is too short. So rather the team target to finish seeing the patients rather than the quality of that care to give (FGD).

Similar concerns were voiced by other palliative care staff. For instance, one staff member interviewed mentioned some aspirations: to have majority of health care workers trained in palliative care in order to support those who need this service. According to interviewees, there is need to increase awareness among palliative care among health workers in Uganda in order to improve palliative care services and not only relying on HAU which has its limitations:

...we hope that in the future anybody in Uganda who needs palliative care, if they access any health worker, that health worker either can give them palliative care or can direct them in the right direction to receive palliative care. Here we are sixteen years and only reaching, not ever reaching 10% of people in Uganda (PCS INTERVIEW 10).

According to the staff interviewed, lack of government commitment of resources to support health care staff for training is another challenge. One interviewee suggest that despite the government's endorsement of palliative care activities and its strong political will & support, it lacked commitment to allocate resources to support the training of health care workers in palliative care:

The Ministry of Health is supporting the work of palliative care, the work of hospice carrying out palliative care. The will, they have a strong will, it's the resources that are limited. It's only that the resources they promise us, we hardly see them. They promise us funds to educate the CPCC³⁰ students....but often they haven't fulfilled their pledges, and you know of course they promised also to be buying for us morphine.....but I think because of limited resources... (PCS INTERVIEW 04).

7.3.2 Practice-linked challenges

7.3.2.1 Opposition to palliative care activities

Staff mentioned that opposition of palliative care activities exists in different forms. According to staff, opposition was classified into health professional's perceptions and beliefs as well as cultural values. To begin with, health care professionals' perceptions about morphine directly or indirectly were perceived to be a barrier or resistance to morphine use. For instance, one palliative care staff interviewed mentioned that there is either resistance amongst health care professionals due to limited understanding or lack of appreciation of palliative care among PLWA. For instance, a story of a doctor is captured in an interview reflecting on how some doctors view the use of morphine in terminally ill patients. According to the

³⁰ Clinical Palliative Care Course

interviews, the health care worker discourages the patient from taking morphine yet the patient was in severe pain:

Just last weekend I was in a regional referral hospital in Masaka and there was this patient suffering excruciating pain. She had been started on morphine, her pain was under control and then she runs out, and the health worker who was on duty told her, you can't take morphine it's going to be too much in your body. And this patient was crying in front of me saying, "I'm not taking it because it is sweet and nice or because it is going to satisfy my hunger, I'm taking it because of pain." (KI INTERVIEW 07)

Efforts are being made to address this problem. Focus group participants suggested that the use of networking with other organizations/health facilities dealing with HIV/AIDS is beginning to improve perceptions of morphine and general understanding of palliative care:

About maybe resistance from other health professionals who are elsewhere. One aspect has been networking and collaborating with such institutions, or such partners, such that they come to understand the concept of palliative care and its application so that they will come to understand the importance of palliative care.. (FGD).

One health care staff who took part in an interview described some experiences at their workplace which shed light on some resistance currently existing:

The reasons, one, that fear of morphine, which was implanted into our training that morphine can only be used for acute pain, and if used for more than two weeks then people will get addicted... In fact, there are some very conservative, I won't name doctors in names, but there are some conservative senior doctors who say I don't want to see morphine used on my patients for a prolonged period (PCS INTERVIEW 09).

According to other palliative care staff, resistance to palliative care is attributed to private practitioners. Participants reported that patients trust private practitioners and therefore confide in them about their problems. In the process they are lured into

believing those private health care providers' dubious claims to be able to treat any conditions including cancers. According to the focus group participants, the qualifications of these private health care providers are not known and they drain the resources of many desperate patients:

I think another challenge is the private healthcare providers. Like many of our patients really confide or trust these other healthcare providers. We really don't know their qualifications, usually the patients may call them my doctor said, the doctor said, so they keep giving other alternative treatments, especially in the case of cancer patients. Like the patients still have hope and they are treating them like they could treat any other curative diseases, so that's also another challenge. You're giving your treatment, and then this other private healthcare providers are also coming to administer different kinds of drugs and fluids, and in some cases the drugs may be very expensive for the families to afford (FGD).

The issue of traditional beliefs interfering with western medicine was also reported. For instance, according to one staff member, traditional beliefs are common amongst the less-educated and those from rural areas. This group believe that traditional doctors can address their palliative care needs and they therefore seek care late at HAU palliative care facilities. In addition, it was noted that traditional beliefs affect compliance and that communicating palliative care concepts to patients who adhere to traditional medicines is a challenge:

Usually traditional beliefs, of course, and culture usually interfere with this Western medicine. Much as we offer palliative care in a culturally acceptable manner, we still experience more culture interfering with the care, the more rural you go, because their patients probably are less educated, they have less facilities, they believe in traditional doctors more, you know, so that's where late presentation also comes in. if you start telling them to prepare for death, they may misinterpret you, or they do misinterpret you, you know, you want our patient to die, although we try to overcome (PCS INTERVIEW 04)

Similar views were echoed by another respondent. According to interviewee, cultures and traditional doctors do interfere with health seeking patterns of PLWA because they first consult them before going to HAU. Respondent reported that patients enrol for palliative care at advanced stage because of that:

....we have the culture, you know, people in Uganda start off by saying, many of them start with traditional doctors, and sometimes they end up here. And, you know, traditional doctors are not very good at making proper diagnosis, so as the illness advances and the pain becomes excruciating and not responding to anything else then they are forced to come to hospice (PCS INTERVIEW 04).

Elsewhere in the data, other forms of beliefs have been reported to cause resistance to treatment and care by some PLWA who hold this opinion: that when once prayed for by some pastors they get healed and so their health is 'restored'. According to focus group, it is reported that some religious leaders and pastors proclaim healing to some patients with advanced AIDS, who in turn stop taking HAART and palliative care services. They then end up with complications and die. Interviews report that spiritual beliefs have caused many challenges including patients lost through these observations as described:

The other challenge for patients when you come here, a patient is sent to the ART centre, starts treatment and is doing well. But there are some ... I don't know, the religious leaders, the pastors tell them you are healed from HIV, and this has caused more problems to HIV patients because they have stopped treatment and they really become sick more when after sometimes, because they don't take this treatment, so this religion also have brought us many challenges and we've lost patients in such a way, yeah (FGD).

7.3.2.2. Palliative care at late-stages of disease

Three palliative care staff mentioned that palliative care interventions are often started in the very late stages of HIV/AIDS and that there are several reasons that contribute

to this. First, individuals do not visit the health facilities for volunteer counselling and HIV testing (VCT) or diagnosis but rather only seek for medical care at symptoms-stage or clinical stage, by which time, for most, their disease is advanced or even in the terminal stages. Staff reported that there are a lot of challenges when palliative care is commenced very late, with little time to address the range of needs patients and families have:

Majority of our patients present very late in the continuum of care. Whereas desirably we'd like to have a patient at diagnosis and here I mean early diagnosis. In Uganda it's different, many patients do not visit health care facilities and therefore early diagnosis is usually out of the way. In fact many of our patients are clinical diagnosed, by the time they come, their tumours are so big, they are obvious, they are on the external parts of their body so it's quite obvious that they are in late stage, and some of them even first present to us in the terminal phase we are limited, we don't get to know them well, we don't get to sort out their spiritual issues well, their end of life care, you know. Issues like will writing, succession planning, we don't get to do them well because of the very short time they spend with us. We normally are able to control their pain within that short time but not the other aspects (PCS INTERVIEW 04)

According to one staff member, people in the community do not fully understand the concept of palliative care and wait until their patient is actually in advanced or terminal phase almost dying to send them to hospice/palliative care program. Interviews report late commencement of palliative care due to perceptions that palliative care is meant for end-stage care:

Some people have the mentality that we care for terminally ill patients. So some of them wait for them to reach that time, that stage in their life, now this one is dying I think maybe Hospice can help so some of them are really sent very late (PCS INTERVIEW 06).

Financial hardships were also reported as a factor behind patients' delay in health seeking. PLWA who are very poor or hard-hit socio-economically and have limited

support were perceived to be those most affected because they lack transport to access treatment in time. According to the interviewees, this particularly vulnerable group is common among PLWA who have been isolated or have partners who are also ill and are too weak to support them:

There are cases where patients have been left without support especially with basic survival needs. These particular cases have increased in the recent past. A case where the breadwinner is a patient and partner/wife or children have to take up a new role of supporting the family, the challenge is magnified. ..you find limited support and many challenges like lack of food, transport, no timely treatment (PCS INTERVIEW 06).

7.3.2.4 Difficulties in following up patients

Staff reported challenges related to difficulties in following up patients. According to the interviews, several factors contributed to this. First, staff reported that they are often unable to trace patients once they are enrolled into the palliative care program. Many factors were perceived to contribute to this including rapid disease progression, changes in location/residence, difficulties in sustaining telephone contact. In addition, poor infrastructures (land terrains and poor roads) and lack of transport was also perceived to contribute to lack of follow up:

It's difficult for us to find out whether they haven't come for the next cycle because they are there dead or, you know, and they have no telephone contacts, so this tradition is difficult. And of course travelling upcountry, the roads are bad when you're doing home care, slippery. We need to have stronger cars; we use more fuel (PCS INTERVIEW 05).

Home based care (HBC) is the most preferred model of palliative care but requires a lot of resources:

You see, palliative care in the context of Hospice Africa may be different models, things like homecare models where you have to use the resources to go and visit the patients in their homes, especially those who cannot come to Hospice, that's also a challenge as it involves resources like cars, even the personnel and so on. So it is really a very big challenge (FGD)

In addition, difficulties related to household poverty were reported which led to lack of transport, late presentation of disease and lack of ability to continue with care and treatment. Interviewees report that some patients lack support at home and they are thus unable to connect with palliative care team or health care staff:

Number one I would say some of these people may be enrolled in programme, but when they get home, they don't have the transport and they didn't mention this when they came the first time. So the person will keep dying in their home until you try to track around and try to use the telephone contact, where are you, what happened? Then you get homes like, I was short of money, I couldn't come back any longer. Or sometimes he is ridden, bedridden that is and the relatives are not willing to keep carrying that patient to hospital, so they may not turn up because of those reasons (PCS INTERVIEW 02).

One palliative care staff member pointed in addition to the fact that some patients are nomads and pastoralists who change their area of residency. It is therefore hard to keep record or tracking systems for this particular group of patients, who are then easily lost in the program:

And then when you come to places like Mbarara which is one of our other sites, you know, the rural areas, the communities there are migratory, they're cattle keepers. They're nomads, they're pastoralists. So they keep moving from place to place and, you know, recording, keeping their records can be difficult. Follow up, sometimes they get lost to follow up especially if they have a patient, you know, and etc (PCS INTERVIEW 04)

One palliative care staff member mentioned that HAU's defined jurisdiction makes follow up of patients difficult. HAU only serves patients who are within 20km radius, making it difficult to follow up patients when patients come outside this jurisdiction. Interviewees reported that patients' relatives are urged to support their access to the services:

Another challenge maybe is the patients outside the catchment area, sometimes follow up is difficult. If they are living beyond 20Kms, follow up becomes difficult. Sometimes we just tell the relatives to come and pick medication for them and report about the patient. Yeah, I think that's also another challenge (PCS INTERVIEW 06).

7.3.2.5. Socio-economic challenges

Six palliative care staff interviewed and participants in the focus group mentioned challenges related to socio-economic impact of HIV/AIDS. Two specific areas emerged from the data: patients' high expectations of economic support in palliative care program and a lack of support at the community and family level.

To begin with, interviewees mentioned that there are high expectations amongst the patients when enrolling for palliative care at HAU. According to one palliative care staff member, some bed-ridden patients have expectations that HAU would support their children who are in school by paying fees, offering transport and meeting basic needs. Interviewees report that these issues are difficult to handle:

Sometimes they complain about the distance and also transport (fare) yeah. And then another challenge you usually have is the social issues; lack of finance, school fees for their children. That's also another challenge because as Hospice we can't provide for school fees for their children, which is a big challenge. Some of them come with great hope of medical and social support.... Usually we counsel them and explain to them the role of Hospice and our limits, yeah. So sometimes we may provide food for some patients in case it's available, because sometimes we get donations for food, so in case it's available we can support them that way, yeah (PCS INTERVIEW 06).

Similarly, participants in the focus group reported same concerns with reports of patients coming to HAU with high expectations of being assisted financially to pay for fees of their children:

So when they come to us they have high expectations of being assisted financially, paying school fees for their children and so on. Sometimes each hospice doesn't do okay. So it's a bit of a problem, it's a challenge actually (FGD).

Staff perceived that some patients are motivated to enrol for palliative care services in order to benefit from support: food, transport and other social services including a scheme to support fees meant for orphans. Furthermore, staff perceived that sometimes needy patients are referred by their colleagues to seek support from HAU even if they do not necessarily need palliative care services per se:

When some who are self referrals come in, oh come in, we enrol them for pain and symptom control. But some of them, that's the only problem when we assess them socially they benefit from like some food and comfort fund. And sometimes there's a scheme for providing school fees for some children, but that's especially for orphans. So some of them may come without pain, and they just want the social services, because some of their colleagues have informed them of what they are benefiting from Hospice, yeah (PCS INTERVIEW 06).

Focus group participants described what they referred to as 'dependency syndrome' characterising some patients who have been in the palliative care programme for a long period of time. Some staff perceived that this category of patients is reluctant to go back to their job or support:

I think another issue is most HIV AIDS patients after they have managed their pain and other symptoms, they get better, or when they are here at least. But then they continue livingsay I want everything to be given back to me. These people don't go back into the workforce to look for jobs, whatever job or create a job, instead they depend on organisations to meet their each and every single basic need, and not all organisations can do that, so that creates a very big challenge (FGD).

Four palliative care staff interviewed mentioned lack of support from the community and family level. It was reported that some family members left their patients on their own to struggle while they looked for means to meet the needs of their patients. In process, patients were left with many emotional needs:

Some of these patients, we visited them within a certain time, and we come back. Others are isolated or they're lonely, they don't have carers, and really in their community it's a big problem. So the community sometimes does not support such a person even though we expect support from the community. You'll find people are all poor, such that the community may need to help such a person either materially or by emotional support, but sometimes they might not have those kinds of resources. For emotional support, they may not have time because they're using such times for their day to day survival needs, looking for those needs. So it becomes a big problem, a big challenge in the community (PCS INTERVIEW 05)

7.4.2 WAY-FORWARD FOR PALLIATIVE CARE SERVICES: VIEWS OF KEY OPINION LEADERS

Introduction

This section reports the views from key opinion leaders about the general context of palliative care and their opinions about the way forward. In brief, key opinion leaders reported issues related to how palliative care policies, advocacies, training and availing morphine can be strengthened and thus improve service delivery.

7.4.2.2 Palliative care policies & advocacies

Key opinion leaders in palliative care in Uganda were asked about palliative care policies & advocacies in Uganda. In their interviews, they all mentioned that palliative care advocacies and policies are well-documented in the Health Sector Strategic Plan (HSSP) illustrating government policy in implementing palliative care since 2000. Inclusion into HSSP meant that palliative care is now part of essential health care provided to every Ugandan at all levels of health care system. In addition, the policy has now been revised in three phases with the third one hoped to be comprehensive and expected to improve integration of palliative care into all health care systems in Uganda. With palliative care now incorporated into government policies there are expectations that government will continue to make it a priority and support it:

It's currently in their Health Service Strategic Plan, in the HSSP..... So the policies are there, and once there's policy that means that the Ministry of Health will make it a priority, and it means that they should put funding available. It doesn't necessarily mean, and it's not always there but, so there should be funding available (KI INTERVIEW 03)

Two key opinion leaders in their interviews mentioned that apart from having palliative care policy in Uganda there is continued advocacy for the WHO public health approach. These advocacies line up four pillars for implementation of palliative care service delivery: drugs, education, policy and support for implementation. Interviewees reported that at least 50% of the country has palliative care services and that advocacy is now focused on integrating it into existing health care system:

You make an assessment of the situation where you're going and make sure that there is a need for the service you have, palliative care, and if there's a need for that service then the fundamentals or the 4 pillars of palliative care delivery should be in place..... At least about 50% of the country there's palliative care. It's not a freestanding

service so it should be integrated in the existing health structure, and that's what we recommend (KI INTERVIEW 05).

One key opinion leader interviewed who is also a government official described how government is committed to supporting palliative care to enable all who need to access the service. This interviewee highlighted hope that there will be increased prescribers and improved access to palliative care services as a result of this policy level commitment:

In a broader sense, we will look to have palliative care accessible to everybody who needs it in this country, and we have asked the Government to put palliative care in our national health policy. It's one of the elements of the best package, and also it is in the strategic plan. In a broader sense, we hope to fast increase the number of prescribers of palliative care, providers generally of palliative care, and secondly also to increase access to palliative care services within our National Health Service in the corrected way (KI INTERVIEW 06)

Another respondent mentioned the need to keep advocating for palliative care to be sustained in the agenda in the Ministry of Health especially given that key staff like ministers at the Ministry regularly change:

We need to have advocacy at every level, and the advocacy actually starts with Government. Now the Ministry of Health people change on regular basis, and they need to be updated on a regular basis as to what it is, because you get a new minister in and he doesn't understand it, or he is not following it up, you know.. (KI INTERVIEW 02).

Key opinion leaders reported the importance of research in influencing policies and practice of palliative care. They reported that there is critical need to demonstrate the role of palliative care amongst PLWA. According to one key opinion leader, research data would influence policy makers, decision makers and stakeholders of palliative care to give priority and support palliative care in Uganda:

I guess the other issue is that there's so little research into palliative care in Africa. When we're fighting competing funds there's very little evidence to demonstrate that palliative care makes a difference in Africa. There is in the rest of the world. In Africa, it's very difficult to demonstrate using data that palliative care is important I think it's about research; it's about demonstrating that patients have unmet needs. It's about demonstrating the fact that, for example, palliative care problems can impinge on quality of life (KI INTERVIEW 04)

In addition, lack of support and recognition of the qualified palliative care staff especially in non-hospice settings where some staff work demoralize trained staff. As a result, the trained staff either get de-skilled or lack momentum to practice:

But also the issues of training, that when people are trained in palliative care, it appears that when they go back into the work setting, in more generalist settings, they lack the momentum to keep practicing, and so that's another reason why drugs aren't prescribed. And it's right if people go back into non-specialist settings who need palliative care to be delivered everywhere. The problem is when people albeit the sole trainee then they find it very difficult to sustain practice I think (KI INTERVIEW 04).

Key opinion leaders interviewed echoed the theme of support as fundamental to implementing palliative care among PLWA in Uganda. All key participants interviewed mentioned the need to advocate for and maintain partnership amongst all stakeholders of palliative care. Stakeholders mentioned include: the government through the Ministry of Health at national level and district levels, palliative care association of Uganda, HIV/AIDS organizations/centres, training institutions, palliative health care workers and health care workers and finally community. Where there is lack of support from stakeholders, it was observed that palliative care staff get frustrated in their service delivery. For instance, one key opinion leader described how

palliative care services are marginalized in the hospital and therefore not given support:

The problem there has been that when these people leave their hospitals to come to Hospice Africa for training, after qualifying when they go back, they're not deployed in such a way as to encourage starting in palliative care. If you came from a paediatric ward, you go back to your paediatric ward, or if you come from a gynaecological ward, you go back to your gynae ward, and they are not giving proper chances to practice or units to start palliative care. That's the major challenge we have, yeah (KI INTERVIEW 01)

7.5 DISCUSSION

It emerged from the interviews with palliative care staff and key opinion leaders that they perceive barriers and challenges to expansion and implementation of integrated palliative care in Uganda. For example, the use or utilization of morphine is hampered by resistance from fellow health care workers affecting its availability to PLWA. Interviewees reported under-dosage of morphine because of a lack of support and a presence of myths about morphine being widespread in the community.

Drug supply is an issue which was reported and takes different dimensions. One is that drugs may be made unavailable to patients due to lack of prescribers/ trained palliative care staff or due to mixed perceptions that staff may not support continued use. Second, due to logistical reasons, drug supply is affected in such a manner that morphine is technically unavailable to patients at the time of need. This second reason may be attributed to the complex bureaucracies affecting smooth drug flow from international to national to local destinations in the country.

Concerns were expressed about challenges related to particular palliative care models. For instance, the home-based care model was perceived to be associated with

challenges related to resource-constraints: lack of staff to offer quality care, lack of transport, limited coverage based on specified jurisdiction and sometimes failure to follow up some patients due to many reasons. These challenges were perceived to be complicated by diverse cultural values which make it challenging to offer culturally-acceptable care to all patients across the board.

Another area that emerged is the relative newness of palliative care concept; this was seen to pose a great challenge in many ways. First, lack of knowledge on palliative care among managers and key leaders in the health sector as reflected in their activities and priorities. It was observed that senior decision makers at the Ministry of Health do not support palliative care activities fully: either in budgetary allocation or by supporting palliative care staff in their area of work.

An area which also emerged surrounds the impact of socio-economic in care giving as well as cultural aspects affecting commencement of palliative care. For instance, lack of resources and basic support to access drug or treatment/ palliative care services made some to opt to utilize readily available traditional healers in their communities. Palliative care staff reported that almost all AIDS organizations including palliative care institutions have got an element of financial or material support in their service delivery. Introduction of this element in their services is meant to support the most vulnerable in the community who are poor or isolated or not supported by their families due to HIV/AIDS. This point is discussed further in chapter four.

Whilst these findings build on the previous studies (Dorothy & Harding 2003; Harding *et al* 2005, Harding, 2007; Maddocks, 2003) which have established perceived barriers to palliative care service delivery, the present study has added a new insight into utilization of traditional healers and their impact on health care

seeking behaviour amongst PLWA. Perhaps, their role and how they can be involved in palliative care in African context needs to be further explored. Whilst Maddocks (2003) in a study done in areas of palliative care education in developing countries reported existence of fear of opioids among health care workers and patients, in the present study, palliative care staff and opinion leaders have stressed the role of training in gradually changing this view. For instance, it emerged from interviews that perceptions of medical workers have equated prescriptions of morphine with addiction or sounding caution on respiratory depression which hasten the death. This myth has posed a threat to pain control and management as studies report under-usage of morphine or under-treatment of pain (Breitbart *et al.*, 1999; Dorothy & Harding, 2003; Morita *et al.*, 2000; Merriman 1993; Peretti-Watel *et al* 2004; Rajagopal *et al.*, 2001). However, interviews reported that with consistent palliative care teaching in training schools, it is hoped that there will be minimal resistance to morphine usage in the future.

Key opinion leaders reported that there are a number of challenges related to poor access to morphine by PLWA. First, despite the government's endorsement of palliative care it lacks political will and commitment through Ministry of Health to support its implementation, especially at district level. Second, there are complex logistical challenges in ordering and supply of morphine to parts of Uganda. The protocol and bureaucracies followed delay the provision of morphine. Whilst previous studies have documented challenges on palliative care service delivery (Downing 2008 ; Logie & Harding, 2005; Logie, 2005; Harding, 2004; Higginson *et al* 2004; Merriman *et al*, 2002; Stjernsward, 2003) the present study has shown that there are efforts from HAU and government to sensitize and increase level of awareness on palliative care activities especially at district levels in order to improve

morphine access. The present study has also shown that through networking and partnership, morphine access can be improved. In addition, opinion leaders have reported that special forums like that of regular meetings organized by Palliative Care Association of Uganda have provided an opportunity for palliative care staff to discuss context-specific solutions to morphine access and generally palliative care.

Studies undertaken (Harding *et al.*, 2005; Logie 2005) show that logistical issues and support of government is paramount yet lacking, however, the present study reveal that there are efforts by HAU in collaboration with government to support palliative care activities. For instance, Harding *et al* (2005) in their survey study to identify current practices regarding palliative care implementation in 12 PEPFA countries (Uganda included) reported common factors hampering supply of morphine ranging from central stores, unreliable stocks and complex bureaucracy. The present study builds on the work of Harding and his colleagues (Harding, 2004; Harding, 2007; Logie & Harding, 2005) that having national policies on palliative care and government endorsement alone is not enough; that there is still need for translation of policies into implementation. Interviewing opinion leaders showed that there are some attempts in the Ministry of Health of Uganda to implement palliative care policies through mobilization of support which is done through country palliative care team composed of several stakeholders. This study therefore recommends further exploration on how country palliative care team address several challenges of palliative care especially at district levels.

Key opinion leaders reported lack of drugs availability as major problem especially at district level where there is reluctant support by stakeholders. According to the interviewees, morphine can only be found in particular districts where there are

trained palliative care staffs. As a result, there is need to train more health care workers in other districts in order to access morphine for PLWA. Whilst similar observation has been reported in other studies in Uganda (Downing, 2008; Harding & Higginson, 2004; Merriman *et al.*, 2002; Stjernsward, 2003), those studies did not take into the account changes that have happened over time. For instance, the present study has reported existence of country palliative care team which is concerned with supporting implementation of palliative care in districts.

The immense needs for palliative care in Uganda because of HIV/AIDS epidemics (MoH, 2004; Okware *et al.*, 2001; UNAIDS, 2010;), mean that palliative care needs to be provided to all who need it at generalist and specialists levels (Harding & Higginson, 2004). However, according to the interviews from both palliative care staff and key opinion leaders reported here, the provision and practice of palliative care delivery in Uganda entails addressing many challenges. PLWA in some districts still do not find the services because palliative care is non-existent and where it exists, it is not supported to serve PLWA in those districts. Whilst similar observations have been reported (Jagwe & Merriman, 2007; Harding, 2007), studies done did not take into account barriers that may hinder provision of palliative care to PLWA. The present study has brought out, through interviews; several challenges related to delivery of palliative care to PLWA and the study has also explored possible ways forward. For instance, according to both palliative care staff and the key opinion leaders, particular challenges are related to the continued support for palliative care graduates or trainees who return to work environments where palliative care is neither understood nor valued. To address this problem, employers are now asked to guarantee that trainees will work in area of palliative care at least for 2 years before being deployed

elsewhere. This strategy like in one study done (Jagwe & Merriman, 2007), will help graduates avoid losing palliative care skills.

Home-based care model used at Hospice Africa Uganda has its own challenges. Interviewing palliative care staff, they reported model-dependant challenges. The challenges are related to many PLWA needing palliative care and yet the coverage is limited. Integrated home-based care model commonly used has its weakness. First, due to insufficient staff and high number of PLWA on the program, staff spent limited time on individual (thus may compromise quality) in order to meet targeted patients per day in a given jurisdiction. Second, there are inadequate resources like transport and additional expectations and challenging responsibilities to deliver for instance supporting PLWA's basic needs: food, transport, comfort fund and sometimes burial support. However, Downing (2008) reports that there is no one single model that suits every country and situation.

Other studies have reported similar challenges of models related to feasibility, culturally-acceptable and effectiveness in every setting. Models for instance that address emotional and social needs in African context have been shown to largely lacking or most non-existent (Harding, 2005; Harding & Higginson, 2005; Logie & Harding, 2005; Merriman & Kaur, 2005). Therefore, as revealed in interviews in the present study, having models of palliative care services evaluated and applying them in local context is necessary. There is one upcoming model for development of palliative care in rural African context known as '*Nankya model of palliative care development*' (Downing, 2008). This particular model still needs to be validated, adapted and applied. There is also need to evaluate its suitability and still needs to

address such important questions like ‘why is there need for model? Or what new value will it bring to already existing models in Uganda and Africa as a whole?

Both palliative care staff and key opinion leaders reported that implementation of palliative care still suffers resistance and lack of support because of its newness or lack of understanding. The number of health care workers trained as specialist palliative care is less than 100 by the time the study was carried out. Some trainee or graduates (CPCC) faced barriers implementing palliative care because of relatively new concept to many. Managers in the hospital or employers of trainees still find difficulties supporting palliative care activities leaving trainees to struggle to deliver palliative care activities in a challenging environment. Whilst there were similar challenges reported in other studies (Downing, 2008; Downing, 2006; Downing, 2007; Munodawafa, 2001), the studies done reflected general challenges which did not include experiences of trainees who return to workplace. However, this study reports views from palliative care leaders on specific challenges in the area of workplace. Though the study attributed to lack of support from managers, it is hoped that managers and leaders will start to appreciate palliative care and support activities in their respective areas including supporting trainees.

Whilst the present study builds on the work of Harding (Harding 2004) which suggested that ‘*what constitutes palliative care needs and services in sub-Saharan Africa is continent specific..page 6*’, interviews has shown that needs of patients stretch beyond palliative care needs to include basic needs as well. According to the interviews, palliative care staff reported that palliative care delivery in Uganda has additional components of financial support for food, shelter, funeral costs and school

fees, respite, spiritual care and orphan care concerns palliative care. Therefore HAU finds a lot of challenges meeting many diverse needs of patients who live in poverty.

Both palliative care staff and key palliative care in their interviews, mentioned that palliative care staff are very few in number and there is need to train more to meet the palliative care needs of PLWA at every level of health care system. Having less than 100 professional staff who deliver palliative care in the whole country is perceived to be indeed a small number. Therefore palliative care delivery in Uganda still encounters a lot of challenges due to shortage of staffs which is a barrier in implementing palliative care throughout the country. As such, HAU has recruited a number of volunteer to support palliative care staff. Whilst the present study builds on the work of Downing (Downing, 2008), it has however shown that sustaining palliative care activities in Uganda is a challenge given the prevailing shortage of health care staffs. Therefore in the interim, volunteers have gained recognition in palliative care provision and are being recruited to form human resource discourse (Anderson 1994; Downing 2008; Downing 2006, Gwyther 2005; Jagwe & Merriman, 2007; Uys 2003). Given that Uganda health sector is the main provider of HIV/AIDS-related services to a population of about 29million people, shortage of health care workers could negatively influence access to and quality of care (Dieleman *et al.*, 2007).

Key opinion leaders reported need to build capacity of health care workers especially in the rural areas of Uganda. This is because majority of Ugandans live in rural areas (UBS, 2002). These findings have been supported previous studies. In one study for instance, it reports that nurses, who are the majority play pivotal, dynamic and

changing roles in the provision of palliative care in rural areas (Downing *et al* 2006). Other studies have reported that there are more nurses available than doctors, though, in many areas they are in short supply and now many home-based care services are run through community volunteers, with nurses supervising them and seeing only the sickest of individuals (Sepulveda *et al.*, 2003; Downing 2007). With approximately 88 per cent of the Ugandan population live in rural areas (UBS, 2002), most staff are nursing assistants, a cadre with minimal professional health qualifications (Dieleman *et al.*, 2007; MoH, 2005). Thus, challenges facing the discipline exacerbated by its workforce are now being composed of volunteers (Downing 2008), however, question of how this problem is tackled remains to be addressed.

Both palliative care staff and key opinion leaders reported challenges related to delayed commencement of palliative care intervention for PLWA due to many reasons. The present study reported many reasons for this. First, influence of socio-cultural barriers in the society or community. Some participants in the study reported to have first consulted witchdoctors or visited traditional healers to solve their problems before enrolling at HAU. This trend does affect their commencement of palliative care and is a great challenge. Second, socioeconomic factors (poverty-lack of support) have also influenced commencement of palliative care. This study therefore has added light into socio-cultural barriers to health care seeking by PLWA which remains to be addressed.

Some health care staff felt they had been affected directly or indirectly in caring for the dying. Some health care staffs reported challenges around this area. Whilst similar findings have been reported in other studies (Delobelle *et al* 2009; Shisana *et al* 2003;

Smit 2005), the present study focused on experiences of caring for patients with advanced AIDS.

Studies have however reported impact of caring to caregiver but in general to all PLWA. For instance, in one study, prolonged care of patients with HIV/AIDS was reported to present a heavy burden of health care workers, traumatizing them emotionally and affecting their personal and family lives (Delobelle *et al* 2009). While in another study, nurses felt demoralized and expressed feelings of emotional and psychological distress but also compassion and empathy for these patients (Shisana *et al* 2003). Studies revealed that challenges of caring for the dying can affect the quality of their care delivery. For instance, studies done have reported that psychological disturbances among health care providers may lead to suboptimal quality of care which could compromise the care (Chandra *et al.*, 2004; Davhana-Maselesele & Igumbor, 2008). From interviews in this study, care givers' needs and psychological well-being has not been well-addressed adequately. Whilst family members (who form the majority of care givers) have a lot of needs, it is quite challenging to address their needs which merits further inquiry on how best to support them in different context.

7.6 CONCLUSION

Both palliative care staff and key informants' perspectives highlight successes, barriers and important lessons drawn for palliative care service delivery in Uganda. To begin with, whilst interviews and focus group reported fear related to the use of morphine, the present study has shown that palliative care staff and key informants

stress important role of training in gradually changing this view. In addition, interviewees emphasised application of partnerships and networking to improve palliative care delivery especially at grass roots levels. For instance, discharge plans (for patients hospitalized) or patients at out-patient from HAU are linked with palliative care staff at community level for continuity of care.

It also emerged from interviews that the concept of palliative care, though relatively new, was becoming known through efforts to increase level of awareness and training programs rolled-out for all health care workers in Uganda. Thus, it is hoped that with increased training and level of awareness, health care staff would appreciate the role of palliative care and that there would be minimal resistance/opposition to palliative care activities.

Further, it emerged that there is an important dimension of traditional healers and cultural aspects that affect commencement of palliative care amongst patients with advanced AIDS. Though the practice of seeking for traditional herbalist was common among the patients in villages and poor, interviews reported need to explore further on how various sociocultural contexts would be addressed in caregiving.

Importantly, the study revealed the significance of collaborating with HIV/AIDS organizations/units, Ministry of Health and community volunteers to promote and expand palliative care. The need for continued advocacy to influence policies and delivery of palliative care, as reported in this study, featured in several ways. First, the study showed that while palliative care policies are captured in government's national policies (HSSP 2011), there was lack of commitment to translate these policies into actions by government which remains a challenge. Second, whilst there are efforts to

increase scope of palliative care delivery service at district level, reducing bureaucracy related to drug supply and improving its access remains a challenge.

In considering how to make sense of the findings in this study in theoretical terms, it is useful to apply structuration theory as a frame. The theory of structuration was proposed by Athony Giddens (1984) in the *constitution of society* which holds that all human action is performed within the context of a pre-existing social structure and that all human action is at least partly predetermined based on the varying contextual rules under which it occurs. He developed the theory of structuration to account for the role of human agency or actions in the production of social structures. Based on its relevancy in explaining findings of this study, structuration theory was particularly chosen to elucidate and give more meaning to actions shaping delivery of palliative care services to PLWA in Uganda.

For the interest of this study, the application of this theory lies in its principal concepts proposed by Giddens who sought to demonstrate that social structures and social actions have a symbiotic relationship (Giddens, 1986; 2009). In essence, they are dependent upon each other such that social structures and social actions cannot exist independently. With that understanding, Giddens further demonstrates that structure is constantly evolving in that it undergoes re-invention process through its social action (Giddens, 2009).

Structuration theory asserts that human action (*activities that promote or hinder palliative care service delivery*) is performed within context of pre-existing social structure (*in this case is health care system*) which is governed by norm (*policies*). In the view of Giddens (2009), human beings as agents possess knowledge of the societal needs (*level of knowledge on palliative care needs for PLWA*) which informs their

action (*response towards palliative care needs*) which finally create a structure (*system or framework/infrastructure in place that address problems-palliative care needs*). Therefore agents (human activities) can reinforce, maintain or generate actions which finally translate to a structure.

Applying these concepts therefore in this study calls for examination of role of agents (human activities) in influencing the four pillars of palliative care service delivery: drug availability, training, policies/advocacies and implementation. Structuration theory refers agents (human activities) as those responsible in causing action (the promote or hinder palliative care activities). In this case, agents can be practice of health care workers in relation to palliative care, or key leaders' actions that affect delivery of palliative care, which in turn will influence and shape actions geared towards responding to palliative care needs of PLWA and create infrastructure to meet these needs.

According to this theory, the challenges encountered in delivering palliative care (both service-linked and provider-linked) can be linked to infrastructure or system in place that seeks to address palliative care needs of PLWA. Infrastructure is a product of actions of agents (human activities) and can be traced to a number of several factors, including: the level of knowledge on palliative care/awareness of palliative care needs of PLWA, level of commitment in implementing policies that relates to palliative care, availing drug, key decisions that affect delivery of palliative care services at national, district and community level. For instance, if at national level, leaders do not prioritize palliative care activities then implementation remains a challenge at district level and at community level because their actions can reinforce, maintain or hinder palliative care activities. Hence, this theory calls for robust system or infrastructure which is

able to address palliative care needs for PLWA through responsible actions geared towards timely meeting of those needs. Important lessons from this theory include assessing and re-assessing (reflexive monitoring) how our actions produce social structure (system/infrastructure) and awareness that these actions can either be favourable or unfavourable to the promotion of palliative care activities.

In conclusion, to understand dynamics of structure and agency, Giddens refers to human action as agency (to be human is to be an agent). Giddens and other structuralists propose that agent's knowledge about society informs their action which in turn reproduces social structure and then reinforces/maintains the dynamics of action (Giddens, 1986; 2009; Gil-Garcia, 2007; Sewell,1992). Therefore, Giddens proposes that possession of agency allows one to break away from normative actions and depending on the sum of social factors at work; they may instigate a shift in social structure (Giddens, 2009). Therefore, this study has given insight into the experiences of palliative care staff and opinion leaders and their perceptions on implementation of palliative care. These views have collectively shed light into how delivery of palliative care activities take place (in certain social structure) which can be re-examined to instigate shift and expand palliative care services amongst PLWA.

CHAPTER 8

CONCLUSION

8.0 INTRODUCTION

The aim of the study on which this thesis is based was to investigate patients' experiences of living with advanced AIDS in Uganda as well as experiences of their caregivers, the majority of whom were family members. Additionally, the study sought to examine the views and opinions of palliative care professionals and key opinion leaders. The research questions addressed were as follows:

The study sought to address the following research questions and objectives:

- 1. How do patients with advanced AIDS (stage III and IV) and with palliative care needs and their families experience care delivery and receipt over a period of 8 weeks?**
 - d) To access patients' and caregiver's accounts of living with HIV/AIDS
 - e) To report problems (if any) encountered by HIV/AIDS patients and caregiver(s) and how these problems change over time.
 - f) To measure palliative care outcomes for HIV/AIDS patients and how they change over time
- 2. How is morphine roll-out programme among advanced HIV/AIDS patients operationalized in Uganda?**
 - b) To describe the processes and practices involved in the morphine roll-out programme among advanced HIV/AIDS in Uganda

- 3. What are the challenges faced by health care workers involved in delivery and implementation of integrated palliative care for patients with advanced AIDS?**
 - d) How do health care workers seek to respond and address patients' and family caregivers' needs in the context of a resource-poor setting
 - e) To discern the obstacles and challenges faced by palliative health care workers involved in palliative care delivery to patients with advanced AIDS.
 - f) To examine the views of palliative care workers on actions that could be taken to develop palliative care delivery in Uganda
- 4. What are the views of key opinion leaders on development of palliative care policies in Uganda?**
 - c) To develop understanding of broader perspectives on, and the context of palliative care in Uganda
 - d) To examine expert views on how palliative care delivery could be improved in Uganda

The study was conducted in three phases in order to address the research questions adequately. In phase one, the study sought to describe and report palliative care needs and problems encountered by PLWA in an advanced stage of illness and their care givers. This was done by using the APCA African Palliative Care Outcome Scale to measure the palliative care outcomes of patients (Harding *et al.*, 2010) and establish how their experiences change over a period of time; in addition, patients and carers were invited to take part in a qualitative interview.

The research protocol set out a plan in which I administered the APCA African palliative outcome (Harding *et al.*, 2010) interview questionnaire on the first day that patients enrolled into palliative care services, with follow up assessments using the

questionnaire on a weekly basis to measure the 10-item indicators of outcome and establish any changes over a period of 8 weeks. In essence, these 10-item parameters measured the impact of palliative care services that patients received over a period of time. These weekly assessments using the African APCA Palliative Care Outcome Scale (Harding *et al.*, 2010) were followed by qualitative interviews that sought to establish experiences of PLWA and their family members. It was assumed that the qualitative interviews would allow detailed description of patients and caregivers' stories to emerge and provide insight into their lived experiences. I have reflected on the development and implementation of the research protocol in the research methods and methodology chapter.

In the second phase, the study sought to understand and describe how palliative health care workers attempt to respond to and address patients' and family caregivers' needs. In this phase, I sought to describe the obstacles/ challenges they perceived to be related to implementation of palliative care amongst PLWA. The third phase focused on developing an understanding of broader perspectives and the context of palliative health care delivery in Uganda, and included an examination of key opinion leaders' views on how palliative care could be improved in Uganda.

This chapter summarises the principal findings of the study as well as its strengths and limitations. The implications of the findings for future practice, education and policy and future research are set out.

This final chapter is divided into three sections. The first section provides a summary of the thesis chapters. Section two outlines the implication and contribution of the study to new knowledge, its significance and limitations.

8.1 SUMMARY OF CHAPTERS

Chapter one provides a background to the study and outlines why such study was important. I provide a brief overview of facts related to HIV/AIDS, the impact of the changing course of treatment modalities and policies related to palliative care. Chapter 2 presents a review of research in the palliative care of PLWA and examines health care provision in Uganda. This chapter helps to situate this study within the context of the wider literature and hence identifies gaps in literature for which research is necessary. Chapter 3 examines the use of the mixed methods of data collection to address the research questions and sets out the methods and methodological procedures used in the three study phases, as well as plans for dissemination and the ethical considerations involved in the study.

Chapter 4 provides a brief overview and introduction of the patient participants in the study. I give brief accounts of each person's situation and the context in which they lived. I also summarise some of my personal experiences of encounters with these research participants and how this process shaped my understanding of patients' and family care givers' experiences and of the methodological issues involved in this study.

In chapter 5, I draw on the qualitative interview data to explore the experiences of patients living with advanced AIDS together with those of their family care givers. The majority of patients had AIDS related cancers, were bed-ridden and experienced distressing symptoms. There was profound poverty amongst the participants due to socio-economic impact of HIV/AIDS, with lack of food and other basic requirements highly in evidence. For those on HAART, while this improved their physical health, in some cases uncertainty about the future was increased, due to difficulties such as

access to services and drugs as well as experiences of side-effects. Some family caregivers also had AIDS which made their roles as care givers even more challenging. Patients and their family caregivers experienced emotional challenges related to disclosure and the stigma of having AIDS. Fear of stigma was reported by them to influence to whom they disclosed and where and how they accessed support. The chapter concludes that there is a great socio-economic impact of HIV/AIDS among households with AIDS. While people with AIDS related cancers access HAART, they have limited or no access to palliative care. More needs to be understood about how to develop models of palliative care in resource poor contexts for people with AIDS.

Chapter 6 provides findings from an analysis of APCA African palliative care outcome scale (Harding et al., 2010) used to measure the outcome of care among PLWA. In this chapter, I discuss the results with a view to triangulate and complement the findings presented in chapter 5. The analysis of data in this chapter shows that experiences of living with advanced AIDS while receiving palliative care services change over time. The chapter provides useful data showing how the APCA African palliative care outcome scale (Harding et al., 2010) can be used to evaluate palliative care services or measure the impact of palliative care intervention. Findings show that pain, symptoms, patient's worry or anxiety, and family's worry or anxiety were high at the beginning (1st week) and it declined due to palliative care service receipt. In addition, scores relating to: sharing their feelings with friends or family members, patient's feelings of being at peace, level of information, family's confidence of taking care and patient's feelings about whether life was worthwhile, increased from week 1 to week 8 of the study.

Chapter 7 examines how palliative health care professionals seek to respond to palliative care needs among PLWA and the challenges and obstacles they face. Amongst the ways in which palliative health care professionals report responding to palliative care needs is through partnership or networking with stakeholders, improving palliative care education and raising awareness of palliative care among the public. Challenges of palliative care delivery are examined in two categories. First, service-linked challenges, which include: lack of knowledge about palliative care in the public, drug supply challenges, inadequate prescribers and lack of trained specialists. Second, facility-linked challenges, which are: opposition to palliative care activities, commencement of palliative care in late-stages, the multiple roles that palliative care professionals play, difficulties in follow up of patients and socio-economic challenges.

This chapter also includes findings from interviews with key opinion leaders or stakeholders in palliative care service delivery in Uganda. The findings from interviews with stake holders are examined using the framework of the WHO public health model approach which calls for: drug availability, national policies for palliative care, palliative care education and support for implementation.

8.2 IMPLICATIONS OF THIS STUDY

This study was aimed at establishing illness experiences and outcomes of palliative care among people living with HIV/AIDS (PLWA) and exploring professional perspectives on palliative care services to enhance care and management of PLWA. The focus and emphasis is on care for PLWA that incorporates palliative care as part

of a continuum of care. The study findings show the importance of care and management based on the multiple dimensions of palliative care: physical, emotional, psychological, social and spiritual. The study indicates a need to put special emphasis on tailoring care and management of PLWA' needs along the above mentioned areas. There is also need to empower care givers who are family members by provision of information about how best to support the patient. The findings of this study have several implications across the dimensions of practice, education, policy and research.

8.2.1 Current practice

Findings from this study seek to inform the practice of palliative care service delivery to PLWA in different ways. The findings reported that experiences and needs of PLWA surround physical, psychological, emotional and spiritual areas. In contrast, the care and management of PLWA has tended towards physical aspects. In addition, health care workers still view palliative care as a new concept. Therefore, the findings of this study show the need for strengthening service infrastructure in such a way that palliative care is integrated in all forms of care and management of PLWA.

Palliative care staff need to work with several key players or stakeholders to address the many psychosocial issues affecting PLWA. Addressing psychosocial issues which include anxiety and worry, HIV/AIDS stigma, disclosure issues, fear related to contracting HIV (by caregivers) is a great challenge. Qualitative interviews and also APCA POS findings show how psychosocial problems are relatively slow to improve in comparison to physical symptoms (for instance, pain).

Specific contributions of this study for the wider spectrum of palliative care for PLWA are discussed below.

First, the findings particularly showed that the provision of HAART as a therapeutic treatment for PLWA left some patients with palliative care needs unaddressed (Harding, 2004, 2007; Harding *et al.*, 2005; Selwyn, Raveis & Sacajiu, 2009). For instance, interviews with patients showed that some took ARVs irregularly; some endured the treatment with difficulty, while some rejected the treatment completely. In addition, the present study has also shown that some use traditional medicine in order to overcome distressful symptoms which have affected compliance and commencement of palliative care services. This observation has two important implications for practice: palliative care staff need to network and establish collaboration with traditional herbalists; and there is a need to train traditional herbalists to identify those patients with palliative care needs and refer them appropriately.

Second, existing research shows that disclosure of AIDS status is an imperative leverage for support (Dlamini *et al.*, 2009; Kalichman *et al.*, 2003; Serovich, 2007), however, this study has shown from interviewing patients that some found disclosure brought with it discrimination and a lack of support. This observation has two implications on practice. First, health care staff need to further develop counselling strategies to support individuals who fear the impact of disclosure on the willingness of family and friends to provide emotional and material support. Second, there is need to have more emphasis on the psychosocial support of PLWA during their treatment. The study findings show that patients found it difficult to access culturally-sensitive psychosocial care, although both qualitative interview findings and results from the APCA-POS interviews confirm how important psychosocial needs were (see also point seven).

Third, interviewing patients has contributed to new understandings of the strategies that patients may use to disclose their health status. Strategies reported in this study included the use of: indirect approaches, intermediation, selective disclosure to trusted confidants and, in some cases, non-disclosure for fear of rejection. Thus, there is need for staff to give attention to communication especially in African context where there are diverse social cultural aspects. In addition, it has also shown that there is need to empower some participants on communication skills when dealing with their children. The palliative care staff also need to understand the dynamics of disclosure and support them where possible because patients differ as to whom they choose to disclose to.

Fourth, another contribution of this study is in providing new insights into the role of the family clan system amongst patients with advanced AIDS. As shown in the present study, majority of these patients suffer from discrimination from those in their immediate society and therefore lack support; they thus often reported a preference to relocate and live with remote clan-mates (relatives) who were perceived to be better placed to offer support. Interviewing patients and caregivers has shown that distant relatives played a key role in helping patients with advanced AIDS to access treatment and support services. This observation has implications for the practice of palliative care staff, who need to be aware of the need to cautiously handle the aspect of confidentiality and disclosure issues when dealing with patients and a range of relatives or clan. In addition, there is need to plan care with the patient's preferred setting of care in mind and to promote key health messages related to prevention and support services for HIV/AIDS through patients' networks, many of which may be wide ranging in terms of distance.

Fifth, whilst existing studies have shown that HIV diagnosis meant loss of support, discrimination and increased suffering due to isolation (Medley *et al.*, 2009), the present study contributes new understanding of how patients attempt to live with stigma. Palliative care staff need to identify patients who are discriminated against and isolated to either offer extra support or link them up with appropriate support or guidance on services available.

Sixth, whereas Lyon and his colleagues view religion as a means of providing emotional support towards PLWA (Lyon, Townsend-Akpan & Thomson, 2001), the present study provide little evidence on the role of religion, however, religious issues were important to some patients. For instance, some PLWA end up more stigmatised and depressed, even in church, as it happened in my study. The implication for practice is two-fold: first, palliative care staff need to network with pastors and disseminate information on experiences of some patients on views of some pastors and church that discriminate and by so doing reduce stigma on HIV/AIDS patients. Second, palliative care staff need to network with pastors to enhance emotional support.

8.2.2 Education

This study has highlighted a number of issues relating to training and need to raise awareness of palliative care activities. To begin with, individual interviews and a focus group with palliative health care staff, and interviews with stakeholders identified the need to strategize means to raise awareness to improve recognition and appreciation of palliative care among health care professionals, managers and policy

makers in Uganda. In this study, palliative care staff and stakeholders reported that managers at district levels in Uganda (DHMT) were either reluctant to support qualified or trained palliative care staff to implement palliative care or generally did not facilitate palliative care services because they were unfamiliar with palliative care as a concept. Whilst a number of studies have reported on barriers to palliative care services in Uganda (Downing 2008; Downing, 2006; Downing 2007), this study has shown some specific challenges related to palliative care service expansion at the district level. Thus, there is need to map out strategies for increasing awareness of palliative care amongst district level managers and health care workers in order to gain their support. This could also reduce resistance amongst some doctors who are reluctant to prescribe morphine to patients for fear of addiction.

This study has also highlighted the need to offer training to family care givers so that they can support their ill relative more effectively. This study pointed out that some family members experience a lack of information and support in their care giving. Whilst studies have demonstrated informational needs (Harding *et al.*, 2009; McInerney, 2001), these studies focused on terminally ill patients in general. Interviewing participants has revealed a need to roll-out training for family care givers and support to care givers in order to improve on the overall care.

The study has also highlighted need to increase capacity of training palliative care specialists or palliative health workers because of shortages of trained or qualified palliative care staff in Uganda. Whilst other studies have shown that shortage of staff is a great impediment to the implementation of palliative care activities (Sepulveda *et al.*, 2003; Downing 2007; Downing, 2008), no particular study has singled out the impact of this for palliative care delivery to PLWA. Key opinion leaders

recommended expanding the provision of courses available in colleges/Universities to include training and education for palliative care. It was further suggested that having short courses on palliative care for health care workers in non-hospice care settings would also help to improve and expand services. Both key opinion leaders and palliative care staff reported an increasing use of volunteers to support palliative care staff at HAU and the subsequent need to increase training to this group.

8.2.3 Policies

This study has indicated the need to strengthen and translate government policies on palliative care into action, i.e. implementation. This study has highlighted that there are complex challenges related to implementation of palliative care. There is a need to focus emphasis on the importance of the government allocating resources to support palliative care activities, especially the support of newly trained or qualified palliative care staff in their work place or in the place of their deployment. The study has shown, from the reports of staff and stakeholders, that there is reluctance to support palliative care activities in non-hospice setting or government facilities.

Unlike previous studies (Harding, 2004; Harding, 2007; Logie 2005; Logie & Harding, 2005), which report on policies of palliative care in Uganda, interviewing key opinion leaders has shown that there still need for government's involvement through Ministry of Health to implement the policies. Interviews with staff and stakeholders have shown that palliative care activities are perceived to have largely remained the business of the non-governmental organization, HAU, but there is need to have government support through its Ministry. Key opinion leaders recommended

that there is need to have Ministry of Health involved to sustain palliative care activities in two ways. First, through continued support for palliative care graduates or trainees who return to work environments. Second, through employers by giving guarantees trainees will work in area of palliative care at least for 2 years before being deployed elsewhere.

Existing research has indicated that palliative care is documented in the Health Sector Strategic Plan in the Ministry of Health, which spells out that palliative care services need to be integrated into existing health care systems (Harding, 2004; Harding, 2007; Logie & Harding, 2005). However, interviewing key opinion leaders indicates that there is little that has been done in implementation of palliative care at grass roots levels. With this view, the study indicates vital need to advocate for morphine and palliative care drugs as part of the Essential Drugs List (EDL). This would therefore mean that Ministry of Health would be compelled to offer palliative care drugs at all health care levels. In doing so, the government would allocate resources to expand palliative care services under minimum health care package policy currently in place.

8.2.4 Research

Some key stakeholders in their interviews reported that there is need for more evidence on which to base practice and a need for research findings to be disseminated to inform all aspects of the implementation of palliative care activities: practice, education, policies. It was reported as a key issue that there is need to use convincing data or evidence that palliative care makes differences in the lives of PLWA, so that policy and decision makers are encouraged to allocate resource and support palliative

care activities. Other studies have also documented similar observations; for example, Harding and colleagues have called for need to support rigorous and robust palliative care research to be done in Africa to inform practice and policies (Harding *et al.*, 2008). There is need to allocate sufficient resources to support growing interest of evidence base that underpin palliative care service provision in Africa as agreed in the Venice declaration relating to palliative care research in resource poor countries (McDermott, 2005). In the declaration, there was an agreement to support undertaking of palliative care research to inform practice and policies (Harding *et al.*, 2008; Straus *et al.*, 2000).

8.3 LIMITATIONS

This study has several limitations. First, all respondents (phase one) were from Hospice African Uganda which is located in Kampala. Therefore the respondents came from environs of a major city, which meant that they enjoyed relatively easy access to palliative care services and other facilities; for instance easy access to treatment centres (HAART). It would be interesting to learn experiences of living with HIV/AIDS in different settings such as more rural environments.

Second, it would be interesting if such a study was to include participants followed up from different stages (stage I, II, III, IV) and compare the experiences of care and support in different stages. A study to look at experience of people living with HIV/AIDS from diagnosis and through to different stages is worth exploring. It will offer opportunity to examine how palliative care needs evolve and change over time.

In addition, it would offer an opportunity to gain insight into how these needs are addressed from diagnosis.

Third, it would also be interesting to gain more insight and understanding of experiences of PLWA using APCA African POS tool translated and validated in African local language. A study using APCA African POS tool validated in African language is worth exploring as this would perhaps give a more African or local original data from indigenous African language. Such widely spoken African language like Kiswahili- spoken by 3 Eastern African countries or Luganda-widely spoken in Uganda- could be used. I encountered limitations due to limited literacy (English or Luganda) amongst participants while using the APCA African POS tool.

Fourth, this study lacked a control group. Therefore, it is difficult to ascertain whether improvement or changes in participant's experiences of living with advanced AIDS are wholly to be attributed to palliative care interventions

Fifth, the sample was too small to conduct complex quantitative analysis like regression analysis in order to ascertain variables influencing outcome of care, although this form of analysis was carefully considered as a possibility. The sample size limited my analysis to descriptive and inferential statistics.

Regarding the tool used (APCA African POS), the practical experiences associated with its use in the field give me an opportunity to recommend some points regarding its application as a data collection tool. First, there is need to publish a manual which will hopefully standardize the reader's understanding of the tool. It will serve as a guide in its application and help in interpretation of the Likert scales. For instance,

while rating symptom distress, the possible responses are [0] no, not at all, [1] slightly, [2] moderately, [3] severely, [4] unbearable, [5] overwhelmingly. Using question 5 of APCA African POS states 'over the last 3 days, have you felt that life was worthwhile? and question 6 reads ' over the past 3 days, have you felt at peace. For this questions, I found it difficult to pose these questions to patients with limited literacy and they asked lots of supplementary questions which were difficult to respond to.

Further, whereas it is advisable to maintain the core part of APCA African POS scale, it is important to consider the uniqueness of problems associated with population (from Africa in particular). Majority of people in Africa setting are largely affected by poverty which if a variable on socio-economic aspect is introduced in the scale it would likely give more insight on data collected. This is because Africa is a resource poor continent and generally there are resource-linked aspects to almost everything in life: care, treatment, support and day to day living which is important part in describing experiences.

8.4 FINAL REFLECTION

As I come to an end of my study at the University of Nottingham, I am aware of how much the journey in the last 3 years has changed me. My earlier feelings of self-doubts on my intellectual capacity have gradually faded and paved way to the growing confidence and enthusiasm at the anticipated prospects of working at this level.

It has been a thrilling and enriching experience to engage in this study. For instance such areas as application of methodological procedures as reflected in a number of chapters. It has not been easy journey though, but when I reflect on this, I

acknowledge the immeasurable support and guidance of my supervisors who knew exactly *what, who and how* to support me at each stage of my study.

Most importantly, in my reflection I would like to share key 'take home' message from this research study. This first part of the study explored the experiences of patients living with advanced AIDS and their family members (care givers) and outcome of care. These experiences provided an insight into palliative care needs for PLWA and their family members and how these change over time. The experiences of patients with advanced AIDS when they enrolled into palliative care services is also important in order to understand how their needs are addressed or not met over time.

The second part of study focused on experiences, challenges of palliative health care workers who seek to address the palliative care needs of PWLA. This important phase brought out salient issues relating to service delivery and facility challenges. The third part of the study focused on stakeholders who provided insights into palliative health care infrastructure in Uganda; how palliative health care services are currently operationalized and their opinions about the way forward.

Patients with advanced AIDS and their family members experienced complex and difficult challenges related to living with HIV/AIDS in the context of extreme household poverty. Patients reported severe pain and other distressing symptoms and difficulties accessing treatment and care. Many patients were bed-ridden, and many had opportunistic infections associated with advanced AIDS or AIDS related cancers. All the patients experienced severe physical & psychosocial problems. However, it was noted in the longitudinal study applying the APCA-POS that physical symptoms such as pain responded to interventions faster than psychosocial problems such as example the patient's or family's anxiety; this needed time and resources to address.

Whilst palliative care staff and key opinion leaders mentioned that oral morphine is offered freely by the government of Uganda to all who are in need, there are challenges surrounding distribution, stocking and prescribing of oral morphine. The government of Uganda is committed in expanding palliative care services through its policies, advocacies and networking with Hospice Africa Uganda to identify strategic ways of scaling up services.

My future plan is to share my study findings and recommendations through publications and forums like national and international conferences or seminars. I hope upon my return to East Africa-Uganda and Kenya (home country) to actively participate in palliative care research and influence practice and policies through dissemination of evidence-based publications. I am particularly interested in carrying out further research in area of palliative care and HIV/AIDS in sub-Saharan Africa. Based on my personal experiences and findings of this study, I will particularly explore a possibility of doing research in the following areas:

- *To conduct qualitative study on palliative care needs of PLWA from diagnosis of HIV/AIDS: implications for practice and policy.*
- *To conduct a qualitative study on needs and challenges of newly qualified palliative care staff in non-hospice settings: implications for practice and policy.*

As I conclude, I feel like it is a brave act to present this study where I have addressed a number of issues relating to palliative care for people living with HIV/AIDS in Uganda in which I have used both qualitative and quantitative approaches. I may be criticised or rather my approach may be criticised, but I hope that the contribution of this study

may be deemed worthwhile. I hope that readers and wider community in the field will benefit from the findings of this study.

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APPENDICES

- STUDY'S APPROVAL LETTERS
- APCA AFRICAN POS TOOL,
- INFORMATION SHEETS: PATIENTS ,CAREGIVERS & STAFF
- INFORMED CONSENTS
- INCLUSION CRITERIA,
- PARTICIPANT'S CHARACTERISTICS (4)

APPENDIX 1: STUDY APPROVAL LETTERS FROM

- 1. UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY**
- 2. OFFICE OF THE PRESIDENT**



Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....

Our Ref:.....HIS 508..

Date:.....28/01/2009

Mr. Wesley Too Kiplangat
Aga Khan University- Kampala
P.O. Box 8842.
Kampala

Dear Mr. Too,

RE: RESEARCH PROJECT, "PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS IN UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **December 02, 2008**. The approval will expire on **July 30, 2009**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Akampurira Innocent
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

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THE REPUBLIC OF UGANDA

OFFICE OF THE PRESIDENT

PARLIAMENT BUILDINGS P.O. BOX 7168 KAMPALA. TELEPHONES: 254851/9, 342834, 343926, 343943, 344028, 230048, FAX: 235459 / 344012

ADM 154/212/01

January 13, 2009

The Resident District Commissioner
Kampala District

This is to introduce to you Mr. Wesley Too Kiplangat as a Researcher who Will be carrying out a research project on **Palliative care for people living with HIV/AIDS in Uganda** for a period of 06 (six) months in your district.

He has undergone the necessary clearance to carry out the said project.

Please render him the necessary assistance.


Verina N. Kakira (Mrs)

FOR: SECRETARY, OFFICE OF THE PRESIDENT

APPENDIX II

APCA AFRICAN POS

PATIENT ID _____ Staff name _____	
Date _____ POS no 1 st <input type="checkbox"/> 2 nd <input type="checkbox"/> 3 rd <input type="checkbox"/> 4 th <input type="checkbox"/> 5 th <input type="checkbox"/> 6 th <input type="checkbox"/>	
ASK THE PATIENT	POSSIBLE RESPONSES
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	<p>0 (no pain) 5 (Worst/overwhelming pain)</p> <p style="text-align: center;">0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p>[] 0 Not at all, no effect</p> <p>[] 1 Slightly-but not bothered to be rid of it</p> <p>[] 2 Moderately-pain limits some activity</p> <p>[] 3 Less severely- pain limits most activity</p> <p>[] 4 Severely-activities or concentration markedly affected</p> <p>[] 5 Overwhelmingly-unable to think of anything else</p>
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days? slight	<p>0 (No not all), 5 (Overwhelmingly)</p> <p style="text-align: center;">0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p>[] 0 No, not all</p> <p>[] 1 Slightly</p> <p>[] 2 Moderately</p>

	<input type="checkbox"/> 3 Severely <input type="checkbox"/> 4 Unbearable <input type="checkbox"/> 5 Overwhelmingly
Q3. Have you been feeling worried about your illness in the past 3 days?	<p>0 (No, not all) 5 (Overwhelming worry)</p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <input type="checkbox"/> 0 No, not at all <input type="checkbox"/> 1 Occasionally <input type="checkbox"/> 2 Sometimes-it seems to affect their (your) concentration <input type="checkbox"/> 3 Most of the time <input type="checkbox"/> 4 Yes, always preoccupied with worry about me <input type="checkbox"/> 5 Overwhelming worry
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	<p>0 (not at all)- 5 (yes, I've talked freely)</p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <input type="checkbox"/> 0 None at all <input type="checkbox"/> 1 Very little given <input type="checkbox"/> 2 Information given on request but would have liked more <input type="checkbox"/> 3 Information given but hard to understand

	<input type="checkbox"/> 4 Information given and understood <input type="checkbox"/> 5 Full information-always free to ask what I want, and talked freely
Q5. Over the past 3 days have you felt that life was worthwhile? [felt good about yourself]	<p>0 (no, not at all)- 5 (yes, all the time)</p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p><input type="checkbox"/> 0 No, not at all</p> <p><input type="checkbox"/> 1 a little</p> <p><input type="checkbox"/> 2 Occasionally</p> <p><input type="checkbox"/> 3 Sometimes</p> <p><input type="checkbox"/> 4 Most of the time</p> <p><input type="checkbox"/> 5 Yes, all the time</p>
Q6. Over the past 3 days, have you felt at peace? (not depressed)	<p>0 (no, not at all)- 5 (Yes, all the time)</p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p><input type="checkbox"/> 0 No, not all</p> <p><input type="checkbox"/> 1 Occasionally</p> <p><input type="checkbox"/> 2 Sometimes</p> <p><input type="checkbox"/> 3 Most of the time</p> <p><input type="checkbox"/> 4 Yes, definitely/ all the time</p>
Q7. Have you had enough help and advice for your family to plan for the future?	<p>0 (not at all)- 5 (as much as wanted)</p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p><input type="checkbox"/> 0 not at all</p>

	<input type="checkbox"/> 1 Yes, occasionally <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Yes, adequate <input type="checkbox"/> 4 As much as I wanted
ASK THE FAMILY CARER	
Q8. How much information have you and your family been given?	<p style="text-align: center;">0 (none)- 5 (as much as wanted) N/A <input type="checkbox"/></p> <p style="text-align: center;">0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <input type="checkbox"/> 0 not at all <input type="checkbox"/> 1 Yes, occasionally <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Yes, but not much as I wanted <input type="checkbox"/> 4 Adequate <input type="checkbox"/> 5 As much as I wanted
Q9. How confident does the family feel caring for ____?	<p style="text-align: center;">0 (not at all)- 5 (very confident) N/A <input type="checkbox"/></p> <p style="text-align: center;">0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p style="text-align: center;">N/A</p> <input type="checkbox"/> 0 Not at all <input type="checkbox"/> 1 less confident <input type="checkbox"/> 2 Sometimes in doubt/unsure <input type="checkbox"/> 3 Confident with occasional doubt <input type="checkbox"/> 4 Confident

	[] 5 Very confident
Q10. Has the family been feeling worried about the Client over the last 3 days?	<p>0 (not at all)- 5 (severe worry)</p> <p>N/A <input type="checkbox"/></p> <p>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></p> <p>[] 0 No, not at all</p> <p>[] 1 Occasionally</p> <p>[] 2 Sometimes-it seems to affect their concentration</p> <p>[] 3 Most of the time</p> <p>[] 4 Yes, always preoccupied with worry</p> <p>[] 5 Severe Worry</p>

APPENDIX III



THE AGA KHAN UNIVERSITY



The University of
Nottingham

**THE EXPERIENCE OF NEWLY RECRUITED PATIENTS AT HOSPICE
AFRICA UGANDA**

I wish to take part in the research study and I am willing to share my experiences regarding the palliative care I receive from HAU over a period of 8 weeks of research study.

I understand that I will make arrangements with the researcher to meet at a time and location which are convenient to me to discuss my experiences with him.

Name of the participant.....

The next possible dates of meeting will be_____

Contact telephone number_____

Physical address_____

If any of your family members would like to talk to me about their experiences of care while you are using palliative care services at HAU please tick in the box below with information of contacts

☐

I am interested to contribute to the interviews and discussions in this study. I am informed and understand the purpose of the research. My contact details are as follows

Name_____

Contact number_____

Physical address_____

APPENDIX IV: INCLUSION CRITERIA

Inclusion criteria

Participants must:-

- Have advanced AIDS and newly enrolled into the HAU facility (registered)
- Be within approximately 6 miles away from the facility (jurisdictions of HAU coverage).
- 18 years and above.
- Give consent.
- Able to communicate either in English or Luganda
- Advanced stage III & IV according to classification by WHO
- Consented to participate in the study.

Appendix V

Proposed harmonized definition of patients with advanced AIDS

(WHO, 2005)

Patients with advanced HIV/AIDS will have any of the following

Any clinical stage 3 or stage 4 disease

Or

CD4 <350/mm³

The following table display the WHO staging guidelines for the purpose of sampling participants (Advanced AIDS) as revised in the year 2005 by WHO, 2005

Clinical stage 3

- Moderate unexplained weight loss (<10% of presumed or measured body weight)
- Recurrent respiratory tract infections (RTIs, sinusitis, bronchitis, otitis media, pharyngitis)
- Herpes zoster
- Angular cheilitis
- Seborrheic dermatitis
- Fungal nail infections of fingers

Conditions where presumptive diagnosis can be made on basis of clinical signs

- Severe weight loss (<10% of presumed body weight)
- Unexplained chronic diarrhoea for longer than 14 days
- Unexplained persistent fever (intermittent or constant for longer than one month)
- Oral candidiasis
- Oral hairy leukoplakia
- Pulmonary TB diagnosis in the last 2 years
- Severe presumed bacterial infections (eg pneumonia, empyema, pyomyositis, bone or joint infections, meningitis, bacteraemia)

Conditions where presumptive diagnosis can be made on basis of clinical signs

- HIV wasting syndrome
- Pneumocystis pneumonia
- Chronic herpes simplex infections (Orolabial, genital or anorectal or more than one month's duration)
- Oesophageal candidiasis
- Extrapulmonary TB
- Kaposi sarcoma
- CNS toxoplasmosis
- HIV encephalopathy

APPENDIX VI



THE AGA KHAN UNIVERSITY

**THE EXPERIENCE OF PALLIATIVE HEALTH CARE WORKERS
WORKING DELIVERING PALLIATIVE CARE SERVICES AT HOSPICE
AFRICA UGANDA**

STAFF PARTICIPATION INFORMATION SHEET

Principal Researcher: Wesley Too

Principal Researcher: Wesley Too

You are invited to take part in an important research study.

Introduction

With 25-50% of patients with HIV/AIDS experiencing pain, it has brought increased the urgency for palliative care services amongst AIDS patients. The

study aims to establish challenges, opportunities and way forward regarding delivery of comprehensive, high quality of palliative care for patients with advanced AIDS and their families who are

using palliative care services from Hospice Africa Uganda. To do this, this research study will draw input from participation and perspective of palliative health care workers on care given to patients with advanced AIDS. All palliative health care staff at Hospice Africa Uganda will be given opportunity to participate in this study to respond and discuss the information obtained in phase one with an aim of gaining insight into end-of life experiences from both patients and care giver.

Methods

The study will involve use of individual interviews or focus discussions to get service related factors affecting delivery of palliative care. You may take part in either interviews or focus discussions or both. It is anticipated that it will take place in convenient place of respondent's choice. This forum will provide an opportunity for you to discuss your experience of delivering palliative care to patients with advanced AIDS and family. The length of an interview is anticipated not to take more than an hour though this may also rely on amount of information received from respondents.

Benefits of the study

It is hoped that this study will impact on the professional practice and shaping delivery of palliative care to patients with advanced AIDS. The results of this study are expected to be considered in improvement of service delivery and overall scaling up of quality of palliative care for patients with advanced AIDS.

Confidentiality

Information obtained while participating in this research study will be kept confidential and anonymised. Personal details will not be disclosed. With permission interviews will be recorded for accurate reporting.

Results

Findings of this research study will be used to provide insight into palliative care for patients with advanced AIDS from professional's perspective. Results of the study will be made available through thesis, publications and conferences. Participants will all be provided with a brief summary of the results.

In conclusion

The research is being conducted by Wesley Too and is supported by The University of Nottingham (UK) and the Aga Khan University-Uganda. Documentations of approval by respective ethics committees (Nottingham, UNCST & HAU) will be attached.

Thank you for your participation and support.

For any further information, please contact

Wesley Too

Aga Khan University, Kampala

P O Box 8842, Kampala

Uganda

Tel: +265 412 343497 –Researcher's office contacts (mobile contacts were provided).

APPENDIX VII : APPROVAL LETTER OF RESEARCH AT HOSPICE
AFRICA-UGANDA

Hospice Africa - Uganda
PO Box 7757
Kampala, Uganda
Tel: 256-41-266863/644
256-41-510089
256-392-766867

Hospice Africa



Ms. Nina Shalita
Chief Executive Director

Tel: 256-41-510087
E-mail: shalita@hospiceafrica.or.ug

E-mail: info@hospiceafrica.or.ug
Website: www.hospiceafrica.or.ug

Hospice Africa Uganda Ethics Committee
C/o Hospice Africa Uganda
P.O.Box 7757,
KAMPALA, UGANDA

21st November 2008

Wesley Too
PhD research Fellow,
Faculty of Health Sciences, School of Nursing,
The University of Nottingham,
8 Floor, Medical School
Queen's Medical Centre
Nottingham NG7 2UH.

Dear Wesley,

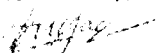
RE: RESEARCH PROPOSAL

Thank you for forwarding your proposal; Topic: **PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS IN UGANDA.**

The Hospice Africa Uganda, Ethics Committee meeting that sat on 5.11.08 at Hospice Africa Uganda reviewed and approved your proposal for Research.

By copy of this letter, you can proceed to submit your proposal to Uganda National Council for Science and Technology

Yours Sincerely,


Dr. Jack G.M Jagwe
Chairperson,
Hospice Africa Uganda Ethics Committee

C.c Uganda National Council for Science and Technology

Patron: Mr. James Mulwanda, Founder, Uganda Manufacturers Association



The University of
Nottingham



THE AGA KHAN UNIVERSITY

**INTERVIEW CONSENT FORM FOR PALLIATIVE CARE STAFF AT
HOSPICE AFRICA UGANDA**

**PALLIATIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS IN
UGANDA**

Principal researcher: Wesley Too

Please tick the box

1. I confirm that I have read and understand the information

for the above study and I have had opportunity to ask

questions

☐

2. I understand that my participation is voluntary and I am free to

withdraw at time without any effect on job

☐

3. I accept to take in an interview for the purposes of research. ☐

4. I agree to use of anonymous extracts from the interviews in published reports and presentations resulting from research. ☐

I understand that all personal details will be removed and I will not be identified in any published work or other output of research.

5. I agree to take part in the above study. ☐

_____	_____	_____
Name of respondent	Date	Signature

_____	_____	_____
Name of researcher	Date	Signature

Appendix IX: Characteristics of patients, their care settings and palliative care

It was assumed that all patients received palliative care interventions which included pain and symptom control during the period of 8 weeks I studied them. The care was received either in patients' own homes, hospitals or at HAU out-patient department. Depending on condition of patient (bed-ridden or not and palliative care need), there were respective individuals who offered particular services. It was assumed that patients received pain and symptoms management, psycho-social support, spiritual support, however it was difficult in this study to establish exactly from whom or over what time an individual accessed the specific services mentioned.											
CHARACTERISTICS OF PARTICIPANTS IN THE STUDY											
Interview code	Participants: Patients with advanced HIV/AIDS only	Age	Marital status/ gender	HIV/AIDS staging	Care setting	HAART or not, Morphine or not The study did not establish when HAART was started	1 st week NEWLY enrolled at HAU	2 nd week	3 rd week	4 th week	8 th Week
KA/05	Agaba	40	Single/ F	IV	O/P ¹ , CBPC ²	HAART, Morphine	✓	✓	✓	✓	✓
KA/07	Adongo	56	Widow/ F	IV	O/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓
KA/11	Amandua	20	Single/M	IV	O/P	HAART only	✓	✓	✓	✓	✓
KA/17	Ddamba	45	Married/M	IV	CBPC	HAART, Morphine	✓	✓	✓	✓	✓
KA/24	Gwandoya	32	Married/M	IV	O/P, I/P ³	HAART, Morphine	✓	✓	✓	✓	✓
KA/04	Kizza	28	Married/M	IV	O/P, CBPC, I/P	HAART, Morphine	✓	✓	✓	✓	✓
KA/08	Kakiiza	23	Single/F	III	CBPC, O/P	HAART only	✓	✓	✓	✓	✓
Follow up study details: All participants were given POS interview weekly as follows: Week 1,2,3,4 & 8. On week 4 all participants were interviewed (qualitatively) and recorded for analysis											

KA/25	Kibuuka	43	Separated/M	IV	CBPC	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/10	Kisomose	48	Not established (abandoned)/M	IV	I/P	Morphine only	✓	✓	✓	✓	✓	Died
KA/02	Lutalo	38	Married/M	IV	O/P, CBPC	HAART, Morphine,	✓	✓	✓	✓	✓	✓
KA/23	Masani	48	Single/F	IV	CBPC,O/P	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/28	Mangeni	47	Single/F	III	O/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/29	Musoke	25	Single/M	IV	O/P,I/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/14	Mugume	53	Married/M	IV	I/P	Morphine only	✓	✓	✓	Died	-----	-----
KA/20	Mugagga	31	Married/M	IV	I/P	HAART, Morphine	✓	✓	✓	Died	-----	-----
KA/21	Nafuna	18	Single/F	IV	O/P	HAART only	✓	✓	✓	✓	✓	✓
KA/27	Nabukwasi	31	Single/F	IV	O/P, I/P	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/12	Nankoma	39	Widow/F	IV	I/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓	Died
KA/19	Nabulungi	47	Divorced/F	III	O/P	Not established	✓	✓	✓	Died	-----	-----
KA/06	Namugera	28	Married/M	IV	CBPC,	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/30	Nakanwagi	30	Married/F	III	O/P, CBPC	HAART	✓	✓	✓	✓	✓	✓
KA/13	Nalongo	29	Single/F	IV	I/P	HAART, Morphine	✓	✓	✓	Died	-----	-----
KA/18	Nabinye	24	Single/F	III	O/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/09	Okello	40	Married/M	IV	I/P, O/P	HAART, Morphine	✓	✓	✓	✓	✓	✓

KA/	Ssematimba	44	Married/M	IV	O/P, CBPC	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/16	Ssalongo	33	Single/M	III	O/P	HAART only	✓		Died		----- .	-----
KA/22	Ssemwanga	43	Married/M	IV	I/P	HAART, Morphine	✓	✓	✓	✓	✓	✓
KA/26	Ssempala	43	Separated/M	III	O/P, CBPC	Not established	✓		✓	✓	✓	✓
KA/15	Wandira	30	Married/F	IV	I/P	HAART, Morphine	✓		Died		-----	-----
KA/03	Zilabamuzal e	60	Married/F	III	O/P, CBPC	HAART	✓	✓	✓	✓	✓	✓

Interview code	Participants: Advanced HIV/AIDS patients only	HIV/AIDS Staging	Theme 1: Pain & Distressing symptoms
KA/05	Agaba	IV	Severe pain related to K/S lesions in the right leg and fatigue, could not walk, in bed-ridden state,
KA/07	Adongo	IV	Pain due to squamous cell carcinoma, fatigued, bed-ridden state. Bone and joint pain related to opportunistic infections
KA/11	Amandua	IV	Appearance of 'chicken-pox' in the body: K/S spots which were painful, fatigued, Headache
KA/17	Ddamba	IV	Persistent cough over one year, chest pain. K/S, co-morbidity: PTB, dyspnoea, dizziness, fatigued
KA/24	Gwandoya	IV	Chest pain, diarrhoea, back pain, PTB, K/S, fatigued, Emaciated and very weak,
KA/04	Kizza	IV	Itchy K/S lesions in the hand, leg lesions (K/S), fatigued
KA/08	Kakiiza	III	Opportunistic infections: oral thrush, lymphadenopathy and K/S feet
KA/25	Kibuuka	IV	Fungating wound in the legs due to endemic K/S legs. Bed-ridden state, fatigued, emaciated and weak.
KA/10	Kisomose	IV	Very painful fungating swollen left feet which looked like elephantiasis. Dehydrated and diarrhoea. 'Seemingly rotting leg which had started to produce maggots & also severely fatigued and anaemic
KA/02	Lutalo	IV	Painful disseminated endemic K/S throughout the body, constipation, K/S lesions on both feet, fatigued
KA/23	Masani	IV	Endless fever, chest pain, cough, seemingly swelling 'rotting' leg, chronic STI & fatigued
KA/28	Mangeni	III	Persistent disturbing fever, fatigue, diarrhoea & vomiting. Cough on and off

KA/29	Musoke	IV	Painful lesions in the legs (K/S), fatigue, dehydrated. HIV wasting syndrome
KA/14	Mugume	IV	Generalized K/S in the body which were painful, co-morbidity: oral thrush and could not eat well, diarrhoea, in bed-ridden state, fatigue, body aches.
KA/20	Mugagga	IV	K/S in the body, anaemic, painful lesions, transfused & breathlessness due to anaemic & fatigue
KA/21	Nafuna	IV	Painful K/S skin spots, fatigue, weak and had opportunistic infections
KA/27	Nabukwasi	IV	K/S lungs which made her breathless, opportunistic infections, cough on and off, emaciated & fatigue
KA/12	Nankoma	IV	Opportunistic infections PTB, -oral and skin, breathlessness, fatigue, painful fungating wounds due to disseminated K/S
KA/19	Nabulungi	III	Opportunistic infections, fatigue, very weak, HIV wasting syndrome
KA/06	Namugera	IV	Disseminated K/S in the body, chronic STI, Lymphadenopathy, opportunistic infections-cough, oral thrush, diarrhoea, very weak/emaciated. Breathlessness & fatigue
KA/30	Nakanwagi	III	Opportunistic infections- oral oesophageal thrush, cough, persistent fever
KA/13	Nalongo	IV	Painful K/S in the body, opportunistic infections-PTB, breathlessness.
KA/18	Nabirye	III	Persistent distressful symptoms despite treatment,
KA/09	Okello	IV	Swollen painful mandible, cough and general weakness, body aches, fatigue
KA/	Ssematimba	IV	Painful disseminated K/S in hands and body, dehydrated and very weak, bed-ridden, fatigue
KA/16	Ssalongo	III	Squamous cell carcinoma, painful lesions,
KA/22	Ssemwanga	IV	Breathlessness, generalized K/S in the body, weak and anaemic in bed ridden state & fatigue
KA/26	Ssempala	III	Squamous cell carcinoma, general body aches, fever

KA/15	Wandira	IV	K/S lungs which caused breathlessness, very weak and now bed-ridden, HIV wasting syndrome & fatigue
KA/03	Zilabamuzale	III	Opportunistic infections-oral thrush, recurrent UTI

Appendix XII: Showing the support needs and support related issues for participants in the study

Interview code	Participants: Advanced HIV/AIDS patients only	Perceived support & needs for patients with HIV/AIDS who participated in the study (family, health workers & disclosure)
KA/05	Agaba	I came to hospice because I knew they would give me medication to reduce on the pain.....all that I expected has been addressed.....the wound (<i>fungating</i>) was so painful but now it is only paralyzed but not painful My daughter has ever brought me herbal medicine... Did not disclose to any family member directly...
KA/07	Adongo	I've had support from daughter and my 3 boys. My daughter lives just around the corner. I see them all the time. After testing (<i>for HIV/AIDS</i>) she didn't tell us, she went to church, so from the church she collapsed... When she came to hospice, she improved in pain.
KA/11	Amandua	Adopted child and brought up by foster parents. Did not disclose easily... You see doctor (referring to PI)....after checking me that I have HIV I handed everything to God...I know God will heal me, when you pray loud to God cant he hear you?
KA/17	Ddamba	When I first started the drugs from the hospice, it gave me problems at first in the area of passing bowel... I was then given more drugs and kept increasing... then the problem stopped. I see now that I have no problems... You see whenever you are sick and staying at home.. you are not eating as you want and you are not getting much support... school fees disturbances... I have seen sometimes he can get hungry at small things, some is not appreciative... but by loving God helps (Ddamba's wife)
KA/24	Gwandoya	At one point I had sort of discrimination but now no more because many people have been affected or infected. I have seen a bid difference, I have only continued having back pain, I couldn't breathe but now I can breathe, I was coughing but now I don't cough a lot. Last time you came you (hospice staff) gave me some sugar and now it is finished and you know I am not working and I am not leaving the house, I have headache and I have no where to get it. May be for the chest I took herbal medicine and it improved The other support like money to buy drugs for cancer because they are expensive we receive much support from church members.... Prayers have also helped....
KA/04	Kizza	I have not told my wife, I fear that she would run away and leave me alone... you see if my knows, she will run away leaving with children and will not know what to do... my sister gives me money to go to hospital..
KA/08	Kakiiza	They were giving me special cup and utensils in my own room. I would be shaking but people live me alone and people would no help me What helped me since I began taking drugs I became strong and gained strength again. Even all symptoms left until nowstaff visit me at home also... Health staff at Butabika (<i>mental hospital</i>) who treated me..counsellor talked to me and also my brother...

KA/25	Kibuuka	<p>When pain comes even if I take that whole green bottle (morphine) the pain is still there... The words the hospice staff told me (counselling) kept strengthening me... Church members do come and pray for me and also paying tuition fees for our last born... I have sacrificed a lot but the support is limited and the leg is not improving....(<i>care giver</i>) My wife know and all my children know that I have HIV/AIDS</p> <p>Church members supported him since he was completely abandoned by family members and no one could trace any information about whereabouts of his family.</p>
KA/10	Kisomose	<p>I live with my brother who gives me transport to hospital and support me....</p> <p>.....about the pain, it has reduced a little bit....the counselling and medicine has helped me very much...your (healthcare worker) advice has helped me psychologically...</p>
KA/23	Masani	<p>I went to hospice and they gave medication... I started seeing difference now I can wear shoes... I was going to local medicinal withdoctors....</p>
KA/28	Mangeni	<p>Hospice as I told you has helped me a lot, there is big improvement even people have noticed...</p> <p>My daughters used to take me to witchdoctors and would give us pounded form of herbal medicine... they were instructed to boil them and give me to drink in plenty.</p> <p>I kept the HIV/AIDS to myself...</p>
KA/29	Musoke	<p>...when you give me drugs (morphine) now the other things which were painning me stopped...counsellors also have been useful because if they were not there from that time till now I would be scared.</p> <p>...now you see the other pain has reduced and now I can sleep...because of the other medicine you gave me (morphine), I did not disclose to anyone in school, they just knew that I was suffering from weird disease which had made my feet swollen...my colleagues would talk about me...even here at the workshop, they see me like anybody else, they look at my legs and I tell them that it is cancer.....</p> <p>Cancer brought me to hospice...toe you are seeing was too painful....</p> <p>Relied on 13 year old child to take care of him in the hospital, was hospitalized for two weeks then he died.</p>
KA/14	Mugume	<p>His wife was also in advanced HIV/AIDS and so relied on his father for support. Was in an in-patient care setting shortly before he died.</p>
KA/20	Mugagga	<p>Traditional 'medicinal soil' that my auntie used to give for my stomach pains and vomiting. They used to boil herbs that increase blood pressure because I was lacking blood.</p> <p>At my auntie's place I just had to care for myself, when illness hit me I struggle on my own until they symptoms disappear....It was difficult to get transport to go to hospital and I would be alone, ..in the hospital drugs were lacking...</p>
KA/27	Nabukwasi	<p>My brother only knows....(<i>HIV/AIDS status</i>)</p> <p>..people at home started to isolate me...you find they say don't use our basin or don't use our cup...use your cup...get your plate...those things I have had many challenges in my life since I got HIV I find myself alone no one helps me when I want something...I am left by myself.. I find solace in God...</p> <p>God is there for me....I have been praying... I even got saved, I told God you know everything, you are then one who created me...</p> <p>My family member see me.. see the symptoms...</p>
KA/12	Nankoma	<p>....morphine from hospice you gave me because I no longer feel a lot of pain and also counselling me about the drugs</p> <p>We are also barely struggling to survive and for that reason we look like we don't want to help but actually we are unable to help....(<i>caregiver</i>) Since her husband died...her children are the ones who take care of her....(<i>care giver</i>)</p>
KA/19	Nabulungi	<p>Was bed-ridden woman who was cared for by her young daughter just before she died shortly after enrolling into the study</p>

KA/06	Namugera	Lived in poverty and relied on selling little vegetables just outside their premises to get money for survival
KA/30	Nakanwagi	Lived with HIV/AIDS partner who relied on friends donations and gifts for survival
KA/13	Nalongo	Was hospitalized shortly she died. Younger sister supported her during her hospital stay
KA/18	Nabirye	Since I came here and I was given some treatment at least there is some improvement and I don't have diarrhoea so much ...you see everyone in Hoima speaks Lunyoro and so when you are there and can't speak Lunyoro the doctors look at you as if you are not a human being... I didn't want my neighbours to know that I have HIV/AIDS....
KA/09	Okello	Now here where we live the person does not give us money, only accommodation, we sleep in the sitting room....we don't know why he doesn't help us.. he also has many problems, he is struggling with many needs so we gamble our way to hospital. Sometimes you meet with somebody (good Samaritan) who feels for us in our situation and gives us like 5000(one pound fifty pence) which helps us to get transport to hospital. That is how we survive.. When people at home discovered that Okello has HIV/AIDS and Cancer they left us so we learnt to be on our own
KA/	Ssematimba	I have become strong and knowing that I will live...it is really good because I have just spent one month and my skin has already become smooth yet I came as if I had leprosy... He wants things of having sex. So I said that you are on treatment so I refused. I am suffering alone...(partner/caregiver). I told my brother that my body is ill
KA/16	Ssalongo	Died shortly after enrolling into program. Relied on his family members for support
KA/22	Ssemwanga	Church, family and friends intervened in his support which included transport and accessing treatment facilities
KA/26	Ssempala	For the last two months I was feeling headache very badly and pain in my body but when I reached your place (hospice).. i was given drugs and now pain has reduced, I can now work Now I went to some pastor to pray for me... Can I get some one? (to marry/relationship after wife separated) No one knows my status not even here at home
KA/15	Wandira	Died shortly after enrolling into study with enormous unmet needs. Seemed to have lacked support in her end of life care.
KA/03	Zilabamuzale	Remained in his rural home which was hard to access and offer support. Died after 3 weeks into the study.

Appendix XIII: Socio-Economic context of participants in the study

Interview code	Participants: Patients with advanced HIV/AIDS only	Socio economic context of the participants
KA/05	Agaba	I have not paid rent for now 3 months and now landlord has issued warning that he would sell my belonging,
KA/07	Adongo	
KA/11	Amandua	In several occasions, the patient wants good food, when you give him what you have, he refuses and do not understand the situation yet there is no money...you know like now I am not working...(<i>carer</i>).
KA/17	Ddamba	After leaving the job I had several friends like my fellow track drivers and my relatives who always think about us...who now help us..... that is how we have managed to survive...
KA/24	Gwandoya	Friends give me thousand (30p) like that... Financial lack is great challenge because the man used to work and now does not work, so the help we get is from relatives and organization like you (<i>care giver</i>).
KA/04	Kizza	He (<i>husband</i>) leaves us only Ush 2,000 (70p) per day for food and taking care of him (<i>patient</i>). We are squeezed in this house as you can see one bedroom house with two families in...(<i>carer</i>)
KA/08	Kakiiza	The situation is not that good, food is lacking sometimes, transport is also hard to get, sometimes you may want to go and pick the drugs

KA/25	Kibuuka	<p>I don't have money and even medical... because the problem is money, I have two children one of them has not gone to school because of money...you want to eat something...fish or meat but you don't have even Ush 100 (1p) not even for sugar....and you are just there bed-ridden.</p> <p>.....friend like you lends me like two or three thousands (3pounds) then when 'matoke' is ready, I sell and repay...that is how we have come this far..</p> <p>....my job was still there but I can't go. My friends run me that my job is still there but I cant go...</p>
KA/10	Kisomose	Abandoned by family members, survived on charitable gifts
KA/02	Lutalo	You know he is bed-bound...now I have got to take care of him and his family.. he cannot support his family anymore...(caregiver).
KA/23	Masaniyou found me lacking soap and paraffin (fuel for kerosene lamp), my brother gives me transport but I am uncomfortable to ask him for other things so I have to fetch around or borrow....
KA/28	Mangeni	Lived in unfinished house without basic facilities like furniture...
KA/29	Musoke	Secondary school student
KA/14	Mugume	Died after three weeks
KA/20	Mugagga	
KA/21	Nafuna	<p>Because they (doctors) had told me to come to hospital and I didn't have money (<i>transport</i>) so I decided to go to Kyebando to request my relatives to assist me... sometimes I had to walk all alone to Mulago hospital which is far... without eating anything.</p> <p>I am a business woman, I deal with items like sugarcane, but since I started taking care of her I stopped my business. I have to be a round her because the children cannot manage on their own (care giver).</p> <p>I can say that we have used all our money in buying food and now don't have money...</p>
KA/27	Nabukwasi	I have spent all my savings/resources and now I am weak, I have had many challenges sometimes I don't have money, rely on

		friends who give money: one give me something today and the following day another brings something.... I would like to eat good food but there is no money, I want to buy drugs but there is no money....I wish I had money to send her (<i>daughter</i>) back to school Since I got sick I have been selling my properties .. now there is nothing that is why I am suffering now...now I ask God I wish.....
KA/12	Nankoma	Lived in abandoned and neglected house with poor ventilation, no lighting and lacked food, sanitary facilities and transport
KA/19	Nabulungi	Died in two weeks, lacked transport to access treatment facilities
KA/06	Namugera	Lacked food, transport and money to access treatment and basic facilities, lived in slum area
KA/30	Nakanwagi	House wife who relied on her husband (who was in advanced HIV/AIDS) who instead relied on friends support for survival & support.
KA/13	Nalongo	Died on the second week, was hospitalized through her time in the study
KA/18	Nabirye	Lived in slums in Kampala
KA/09	Okello	Sometimes you meet with somebody who feels for us in our situation and gives us Ush 5000 (1 pound and 50p) and sometimes Ush 2000 (75p) which helps us to get transport to hospital....that is how we survive. We explain our situation some help some do not...
KA/	Ssematimba	We had a land that we could generate some money but they have sold it and it is finished. We have sold other items to care for the patient (<i>caregiver</i>).
KA/16	Ssalongo	Died on after the second week of enrollment
KA/22	Ssemwanga	Living in lack. Survived on little money, food and lack means to access transport
KA/26	Ssempala	Casual laborer who is supported a lot by his employer to access treatment




KA/15	Wandira	Died after two weeks	
KA/03	Zilabamuzale	Lived in rural home in poverty, died on after the third week	

Appendix XIV: Inclusion and exclusion criteria: phase two (palliative health care workers)

- Involved in direct delivery of palliative health care services at HAU (clinical)
- Above 18 years
- Stationed at HAU-Kampala
- Serve patients who are over 18 years old
-

A map of Uganda showing districts with CPCOs and morphine, with morphine but without CPCOs and those with CPCOs without pc services



-  Districts with PC services and CPCOs
-  Districts with PC services but without CPCOs
-  Districts with CPCOs but no PC services

PC-means palliative care

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