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**PALLIATIVE CARE NEEDS OF CHILDREN
SUFFERING FROM AIDS, ZIMBABWE**

E. GARANGANGA

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PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

BY

EUNICE GARANGANGA

**Dissertation submitted in partial fulfilment of the requirements for the degree
of Masters in Nursing in the Faculty of Health and Wellness Sciences at the
Cape Peninsula University of Technology**

Supervisor: Associate Professor M. Clarke

Co-supervisor: Dr E.M. Gwyther

Bellville

August 2009

DECLARATION

I, Eunice Garanganga, declare that the contents of this thesis represent my own unaided work, and that the thesis has not previously been submitted for academic examination towards any qualification. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.

E Garanganga
Signed

25. 8. 2009
Date

ABSTRACT

Background

By the end of 2007 an estimated 22 million people in sub-Saharan Africa were living with HIV/AIDS. Of these, 1.8 million (33%) were children under the age of 15 years. The epidemic has left 11.6 million children orphaned by AIDS. Zimbabwe has an estimated population of 12 million people; its HIV infection rate amongst all adults was estimated at 33.7% in 2002, decreased to 15.1% in 2007: most likely due to extensive prevention campaigns that were held by the Ministry of Health and Child Welfare, in partnership with other stakeholders. Despite the decrease in infection rate, 1.3 million people live with the HIV/AIDS and 140 000 have died. United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organisation (WHO) (2008) reported that of the 1.3 million people 120 000 were children and 1 million children had been orphaned due to AIDS in Zimbabwe. Only 3% of children living with HIV/AIDS were on anti-retroviral therapy (ART) due to lack of anti-retroviral (ARV) paediatric formulations drugs. The purpose of the study is to determine what palliative care services are available for children diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The aims of the study are to: describe the palliative care services offered by the public health sector to children diagnosed with AIDS; describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS; describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided.

Method

The research design was primarily qualitative with a quantitative component. This research used a descriptive and exploratory study design.

Results

The Public Health Sector's emphasis was on providing medications to manage symptoms, opportunistic infections and providing ART. The NGOs had a strong counselling component in bereavement care and counselling services for emotional, spiritual and social issues and provided limited food, schooling, play/toys and medicines. This study found that needs of AIDS diagnosed children were food 19 (86%), recreation 16 (73%), clothes and blankets 11(50%), educational 9 (41%) and medicines 7 (32%).

Conclusion

The needs of children in palliative care in Zimbabwe are not met in accordance to their expectations by any one of the current service providers. The needs of these children are very basic and can largely be offered by community members.

Key words: Children in palliative care, Needs of AIDS diagnosed children, Palliative Care, Zimbabwe.

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DEDICATION

This research study is dedicated to my husband Milton and my children Kincade, Alaric and Pimpernel.

LIST OF ABBREVIATIONS

APCA	African Palliative Care Association
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretrovirals
HAART	Highly Active Antiretroviral therapy
HIV	Human immunodeficiency Virus
OVC	Orphans and Vulnerable Children
POS	Palliative Care Outcome Scale
TB	Tuberculosis
WHO	World Health Organization
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
MOH & CW	Ministry of Health and Child Welfare

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CHAPTER ONE

INTRODUCTION

1.1 Background

UNAIDS and WHO (2008) reported that by the end of 2007 an estimated 22 million people in sub-Saharan Africa were living with HIV/AIDS. Of these, 1.8 million (33%) were children under the age of 15 years. An estimated 1.5 million died from AIDS. The epidemic has left 11.6 million children orphaned by AIDS. In sub-Saharan Africa, Zimbabwe is the country that has been severely affected by HIV/AIDS pandemic with 1.3 million people living with HIV/AIDS and 140 000 have died. Of these 120 000 children were living with HIV/AIDS, and 1 million children had been orphaned due to AIDS in Zimbabwe.



Figure 1.1: Map of Zimbabwe showing neighbouring countries

(Adapted from Surveyor General, Zimbabwe 2000)

1.2 Public health care facilities: Zimbabwe

Public health care in Zimbabwe is provided at four different levels: i) Clinics, NGOs, Faith Based Organisation; ii) district hospitals; iii) provincial hospitals including Mission hospitals and iv) central hospitals. In Harare there are two public health care central hospitals. One of these two is the Central Hospital and the other is a Children Hospital.

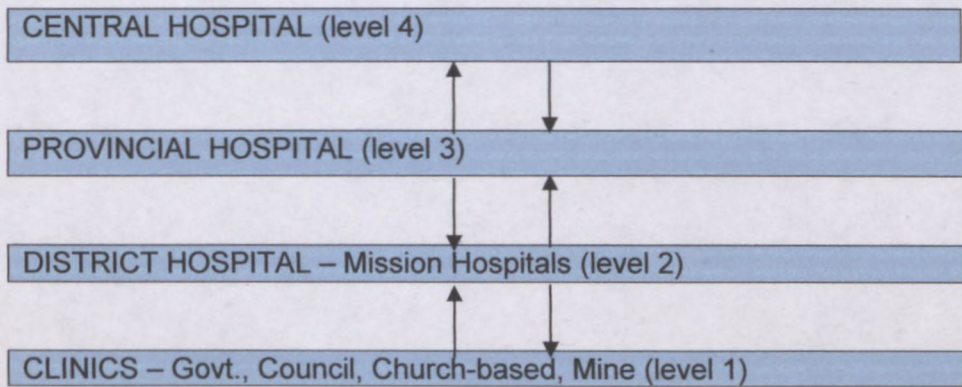


Figure 1.2: The Health Referral System according to Ministry of Health and Child Welfare's different levels of care, Zimbabwe

1.3 HIV and AIDS Situation: Zimbabwe

Zimbabwe has an estimated population of 12 million people. UNICEF (2002) reported that the HIV infection rate amongst all adults in Zimbabwe was estimated at 33.7% in 2002. Zimbabwe was rated third highest country globally. At the first Zimbabwe National HIV/AIDS Conference (June, 2004), the HIV infection rate of the population was estimated at 24.6%. Although Zimbabwe remained one of the worst hit countries in the world, the rate has dropped significantly from 24.6% to the current 15.1% of HIV infection; however the Zimbabwe Ministry of Health and Child Welfare (Zimbabwe MOH&CW) (2005) reported that the problem remains a major challenge for the health care system to overcome. Possible reasons for the drop in the infection rate can be attributed to the intensive HIV prevention campaigns undertaken by the country and possible underreporting.

While the adult HIV prevalence in Zimbabwe has declined from 24.6% in 2003, 20.1% in 2005 to 15.1% in 2007, the HIV/AIDS burden has continued to increase (Zimbabwe MOH&CW, 2007).

The statistics above show that large numbers of children are infected and affected by HIV/AIDS. Erikson (1963) developed and described eight developmental stages through which a healthily developing human should pass from infancy to late adulthood. Throughout these stages, Erikson emphasizes that a person needs the following components right from infancy; adequate caregiver relationship, stability, guidance, safe environment,

encouragement, acceptance and continuity. "Each stage builds on the successful completion of earlier stages. The challenges of stages not successfully completed may be expected to reappear as problems in the future" (Erikson, 1963: 273).

Hence AIDS-affected children in Zimbabwe are not only dealing with the impact of the disease on their health, but with a childhood traumatized by the loss of family members and having to cope with adult responsibilities before having gone through the stages referred to by Erikson. Rather, these children are often both sick and bereaved. They also go through a period of anticipatory grief at the prospect of losing own life. Marston, Defilippi, Marcus, Nasaba and Nieuwmeyer (2006) highlighted that the children would have lost their childhood, loss of a home, loss of self-esteem through stigmatisation and loss of dreams for their future. They would have taken adult responsibilities such as caring for their sick parents, having to find food for the siblings, coupled with poor access to health services, inadequate nutrition, living in poverty, unable to attend school and unable to interact and play with peers. These are vulnerable children who are often abused sexually and forced into child labour and are sometimes forced to live in the streets.

The Zimbabwe Ministry of Health and Child Welfare (2006a) reported that health services for children are treated as a separate programme even within organisations that are providing palliative care. The integration of palliative care of young patients and bereaved children below age of 18 years are lacking; possibly as public health services aim to meet the disease prevention needs and growth development of children 0-5 years old.

UNICEF (2002) reported that children's health issues in Zimbabwe are often overshadowed as children cannot make decisions concerning their health without the help of adults. The researcher's general observation is that most adults find it difficult to communicate with children and this may lead to late diagnosis. Therefore appropriate care and support for children is often started at the late stage of the HIV and AIDS disease. There are many child-headed families due to HIV and AIDS pandemic making the children very vulnerable.

UNICEF (2006) further highlighted that the children are vulnerable due to sickness, loss of parents and poverty. Protection, care and support for children affected by HIV and AIDS are therefore essential.

Further, large numbers of people including children, are in need of treatment for opportunistic infections at public hospitals due to the HIV pandemic. These hospitals find it difficult to cope with the increased costs of care and high demands for care, as patients now require frequent admissions into hospitals for short periods. While Ritchie (2008) highlighted the need for

children to be cared for in hospital for short periods, the ideal place of care for them would be to care for them at home in the context of their families. Hence, palliative care is necessary to integrate into community home based care in Zimbabwe.

1.3.1 Vertical transmission of HIV infection

Zimbabwe Ministry of Health and Child Welfare (2004a) explains that vertical transmission means that an infected mother can pass HIV virus to her child while in-utero, during labour, during delivery and through breast feeding. A total of 116 279 pregnant women were registered and attended to, at sites set for Prevention of Mother to Child Transmission programme. Out of these new bookings 75 226 (65%) were pre-test counselled for HIV test, 54 742 (73%) were tested for HIV of whom 22% were HIV positive. Four hundred and thirty two exposed infants were tested at 18 months and 96 (22.2%) were HIV positive.

WHO, UNAIDS and UNICEF, (2008) reported that prevention of peri-natal transmission of HIV virus from mother to child (PMTCT) must always be the foundation of preventing children from being infected with HIV. PMTCT programmes were started in 2000 and were significantly expanded across Zimbabwe by the end of 2005. However, for those thousands of children who are already infected, and for those infants who fall through the "safety net" of PMTCT and continue to acquire HIV peri-natally, there is need to ensure comprehensive care and treatment.

1.3.2 Sexual Behaviour of Young Adults

UNICEF report (2004) has revealed that in Zimbabwe a total of 55% of those infected by the HIV virus are women and girls between 15 – 19 years that are the most vulnerable. This reflects that the impact of AIDS is expected to be most severe among young adults and children <5 years of age. It is desired therefore that palliative care services be strengthened at all levels of care in order to meet the needs of children and adults affected by HIV and AIDS.

Zimbabwe Ministry of Health and Child Welfare report (2003) revealed that HIV prevalence by sex and age as; women aged 15-19 years (11%), 20-24 years (26%) while men aged 20-24 years (9%) and 24-29 years (24%).

Lastly the high HIV prevalence rate coupled with the high levels of poverty and high cost of living have resulted in fewer people able to cope with the HIV infection leading to rapid deterioration of the health of the poor (Zimbabwe MOH&CW, 2006b). In this scenario many children are the most affected and are at risk of not accessing health care and support. The

economic situation in Zimbabwe has also deteriorated to the point that basic needs of children more importantly food, can no longer be afforded by many families. This leads to low immune system and high morbidity and mortality rates.

1.4 Global Overview of HIV and AIDS, Care and Treatment

UNAIDS and WHO (2008) reported that HIV infected infants and children constituting 90% of all infected children acquire HIV from their mothers during pregnancy, labour and delivery, or post-natal during breastfeeding. The children are infected by HIV from their infected mothers while in utero, during birth and breastfeeding. In 2004, UNAIDS estimated that 5.6% of people living with HIV and AIDS, 13.1% of new infections and 16.5% of deaths were among children aged less than 15 years. An estimated 660 000 children, 56% of them were in Sub Saharan Africa. These children were in need of ART. Another 4 million, 87% in Sub Saharan Africa, were in need of cotrimoxazole prophylaxis (UNAIDS, 2004). The situation however put 32% of children at risk of dying before the first birthday and 52% by the second birthday. Without ART treatment, approximately half of children with peri-natal HIV infection will die by age of two years, as HIV is more difficult to diagnose in children than adults. Available antiretrovirals were initially developed for adults, and most standard fixed dose combinations are not appropriate for children. Therefore there is need to increase the availability of paediatric regimes (WHO *et al.*, 2008).

1.4.1 Vulnerable population/children

UNICEF (2002) stated that children are among the most vulnerable groups in society. The situation is compounded if the children are orphans, abandoned, have sick parents, are sick themselves or are living in the streets. The HIV pandemic has complicated problems of child abuse and AIDS scourge which, accompanied by certain myths and misconceptions has made many children to become vulnerable to HIV infection. Jackson (2002) stated the myths that sexual intercourse with a minor will cleanse the adult of HIV infection means that many children are susceptible to getting HIV infection. Jackson (2002) further stated that any child is vulnerable as he/she has not yet acquired the physical, emotional and the social abilities required to adjust and cope independently with life. Children diagnosed with HIV and AIDS are even more vulnerable due to the wide range of problems being impacted on them. These can dramatically affect the children's quality of life.

UNICEF (2006) reported that the advent of HIV and AIDS has resulted in a reversal of roles with more children becoming involved in caring for siblings and ill adults. Caring for a loved one is emotionally stressful both to the carer and the person who is being looked after, especially if the carer is only a child. Orphans and vulnerable children require psychosocial

support to deal with chronic trauma resulting from them caring for, and witnessing the illness and death of their parents and sometimes their siblings. Discrimination and social stigma associated with their parents' illness and death further compounds the children's emotional stress.

1.5 Overview of HIV and AIDS, Care and Treatment in Zimbabwe

Zimbabwe Ministry of Health and Child Welfare (2006c) reported that antiretroviral therapy (ART) was started in the public sector in April 2004 using fixed dose combinations for first line therapy. From January 2005 to April 2006, neither suspension formulations nor paediatric dose solid formulations were available for use in children. Children weighing more than 15 kilograms were being given adult formulation drugs by using various combinations of divided or crushed tablets in single drug or fixed drug combinations. The Zimbabwe Ministry of Health and Child Welfare (2006) reported that 342 000 people are in need of ART. By September 2005, around 18 000 people were receiving antiretroviral therapy (ART). By April 2006, some 2 097 children above 5 years of age, or had a body mass of at least 15 kilogramme were enrolled in ART programmes through the public sector. This was a disproportionately low number representing around 3% of children living with HIV/AIDS needing treatment. Children below the age of 5 or weighing < 15 kg were not accessing ART because of lack of ARV paediatric formulations drugs. However, Zimbabwe Ministry of Health and Child Welfare acknowledged, "As a nation we had failed to adequately consider the plight of children mostly those below the age of 5 years. Ideally 20% of the total number of people on ART should be children". (Zimbabwe MOH&CW, 2006c:2).

In 2007 estimates from Zimbabwe Ministry of Health and Child Welfare indicated that in Zimbabwe over 342 000 people were in need of ART, however, only just over 105 000 are currently on ART both private and public sector. Out of the 105 000 people on ART only 9 000 (0.8%) are children. Since the introduction of anti-retroviral drugs that reduce the viral load, better management of the disease is possible through controlling opportunistic infections and through good nutrition; people can live longer and have more productive lives. Social, psychological, physical and other non curative support services become critical for the well-being of people living with HIV and AIDS including children.

Zimbabwe Ministry of Health and Child Welfare (2006c) indicated that in March 2006 the Clinton HIV and AIDS Initiative donated ARV paediatric formulations to support 1 000 children in Zimbabwe. The paediatric formulations of antiretrovirals and cotrimoxazole prophylaxis for children living with HIV were designated for use in public health sector sites. The drugs were for use on children weighing < 15 kg for first line ART therapy only. The Zimbabwe Ministry of Health and Child Welfare designated 11 public health sites for children

to access the Clinton HIV and AIDS ART drugs. These sites were called "Learning Sites", as they were seen as pilot sites for subsequent expansion of the ART treatment for children. The learning sites were selected from the 48 sites providing ART and were already treating children. The sites included central, provincial, district and Mission hospitals in both urban and rural areas.

Zimbabwe Ministry of Health and Child Welfare (2006c) reported that by April 2006, 2 097 children < 15 years were receiving ART and 6 466 children were on Cotrimoxazole prophylaxis within the public sector health facilities. More children within the private sector are being treated, but are not yet well quantified.

1.6 Palliative Care

Sepulveda, Marlin, Yoshida and Ullrich (2002) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem 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 (2007a) describes quality of life as the provision of pain relief and management of other distressing and debilitating symptoms. Quality of life dimensions of palliative care are achieved when patients' physical, psychological and spiritual needs are managed from diagnosis as well as the families' social, psychological and spiritual needs.

1.6.1 Palliative Care for Children

Palliative care for children is a special field closely related to that of adults and it applies the principles of other long term conditions in children (WHO, 1998). It optimizes the quality of life for children living with life threatening illness such as HIV/AIDS through the active anticipation, prevention, and treatment of pain, symptoms and suffering. It requires an interdisciplinary team of health professionals and non-professional staff working together for the benefit of the child and his/her family. In light of HIV and AIDS palliative care is an essential component of a comprehensive package due to variety of symptoms that can be experienced such as diarrhoea, pain, cough and fatigue.

Roux, Adams and Barigye (2006) highlighted that palliative care provided from diagnosis of HIV infection, through advanced disease of AIDS is the approach that best delivers the holistic care needed by children living with HIV/AIDS.

1.7 Research problem and questions

UNAIDS and WHO (2008) reported that in Zimbabwe, 120 000 children below age of 15 years are living with HIV/AIDS, and an estimated 1 million children below 18 years old were orphans due to HIV and AIDS . Therefore children are often both sick and bereaved.

On the other hand the Zimbabwe Ministry of Health and Child Welfare (2006c) highlighted the magnitude of the problem as follows: 72 000 (approximately 44%) children living with HIV and AIDS are below the age of 15 years and are in need of antiretroviral therapy (ART); about 45 000 children died in 2003 due to HIV and AIDS; and in the absence of any intervention, a further 40 000 children will acquire HIV through mother-to-child transmission each year, despite the fact that effective Prevention of Mother to Child Transmission protocols could be used.

With this background, it is noted that many children would require comprehensive health care services that includes palliative care in Zimbabwe, as it is also a crucial component of health care, since there is a high prevalence of pain and symptoms throughout the HIV disease trajectory which needs to be managed and controlled. However, it is not clear what palliative care services are available to children diagnosed with AIDS in Harare, Zimbabwe. It is also not clear if the services provided meet the palliative care needs of the children.

What palliative care services are provided to children diagnosed with AIDS in Harare, Zimbabwe and do the available services meet the palliative care needs of the children?

1.8 The purpose and aims of the study

The overall purpose of the study is to determine what palliative care services are available for children diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The aims of the study are:

- To describe the palliative care services offered by the public health sector to children diagnosed with AIDS
- To describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS
- To describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided.

1.9 Approval to Conduct Study

Before the study was carried out, approval from Research Faculty Committee and the Research Ethics Committee situated in the Cape Peninsula University of Technology was obtained, 7 September 2007 (Annexure 2). Since the study would be carried out in

Zimbabwe approval was obtained as well from the Medical Research Council of Zimbabwe in Harare, Zimbabwe, 3 May 2008, (Annexure 3.1) and (Annexure 3.3).

As Ministry of Health and Child Welfare is responsible for all health care issues in Zimbabwe, permission was sought from the Director, AIDS and TB Unit, Ministry of Health and Child Welfare, to conduct an interview with the National Coordinator, AIDS and TB Unit in order to establish the Public Health Sector services available for children clinically diagnosed with AIDS in Zimbabwe and also to conduct the study at the selected organisations (Annexure 1) and (Annexure 1.1).

Access and permission were sought to conduct the study on the NGOs' services provided for children clinically diagnosed with AIDS in the three selected NGOs and to conduct interviews with the managers who were responsible for the provision of care for the children and their families (Annexure 5.1), (Annexure 5.2) and (Annexure 5.3). Children (0-18 years) diagnosed with AIDS in the care of three selected Harare-based non-governmental organisations offering palliative care, were included in this study. Two of these institutions were community based organisations (CBO) and the other was a faith-based organisation (FBO).

1.10 List of definitions

The following definitions will apply to this study.

Advocacy: When you speak up for your rights or the rights of others. In this study a child advocate is an independent adult appointed to represent the best interests of children (Schenk & Williamson, 2005).

Antiretrovirals (ARVs) are the medicines that can be given to prolong the quality of life for people living with HIV and AIDS. They improve the immune system, slow the progression of HIV to AIDS and reduce opportunistic infections (Zimbabwe MOH&CW, 2005a).

Antiretroviral therapy (ART) refers to the correct provision of ARVs with adherence support and all the appropriate care that includes several components such as nutrition, counselling, treatment of opportunistic infections and infection control (Zimbabwe MOH&CW, 2005a).

Assent: Affirmative agreement of a child (Schenk & Williamson, 2005).

Bereavement: The physical loss of something valued (person or object) for example death of someone close. In this study it refers to the death of someone close (Southern African AIDS Training Programme, 2001).

Child or minor: Any person under the age of 18 years (Zimbabwe Government, 1999).

Confidentiality: A condition under which the information revealed by an individual participant in a relationship of trust will not be disclosed to others without permission (Schenk & Williamson, 2005).

Ministry of Health and Child Welfare levels of referral system: This refers to the following levels; i) Clinics, NGOs, Faith Based Organisation; ii) district hospitals; iii) provincial hospitals including Mission hospitals and iv) central hospitals (Zimbabwe MOH&CW, 2006).

Palliative Care: An approach that offers total care to people who are sick, the bereaved and families including children, paying special attention to physical, emotional, social and spiritual needs that are culturally appropriate (Adapted WHO, 2002).

Psychosocial support: "An ongoing process of meeting the emotional, social, mental, spiritual and physical needs of a child. This is done through ongoing care and contact with the child" (Walker, 2005:11-12).

Vulnerable: When a child or adult's survival, care, protection, wellbeing or development maybe compromised due to particular conditions, situations or circumstance and which prevents the fulfilment of his or her rights (South Africa. Department of Social Development, 2006).

1.11 Proposed Study

In Chapter 1, the background to the study, public health care facilities in Zimbabwe, HIV and AIDS situation in Zimbabwe, overview of HIV and AIDS, care and treatment in Zimbabwe, research problem and questions, palliative care, purpose and aim of the study are presented. Chapter 2 will present a literature review on palliative care in children, palliative care and HIV and AIDS, HIV and AIDS and home based care in Zimbabwe, challenges in providing palliative care to children, children and access to care and treatment, developmental needs of children and conceptual framework. In Chapter 3 the research methodology will be presented. In Chapter 4, the findings of the study will be presented, and in Chapter 5 discussions on findings will be presented. Chapter six presented concluding remarks and recommendations.

1.12 Summary

The chapter highlighted the background which showed that 1.3-million people were living with the HIV/AIDS and 140 000 have died in Zimbabwe (UNAIDS and WHO, 2008). Of the 1.3 million people 120 000 were children and 1 million children had been orphaned due to

AIDS in Zimbabwe. The aim of the study is to establish whether the palliative care needs of children (0-18 years) diagnosed with AIDS were being addressed in Harare, Zimbabwe. The rationale for this study is that large numbers of people including children are in need of treatment for opportunistic infections at public hospitals due to the HIV pandemic. In Zimbabwe about 72 000 children living with HIV and AIDS were below the age of 15 years and are in need of antiretroviral therapy (ART) was also presented. In Chapter two the literature review for this study will be presented.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The overall purpose of the study is to determine what palliative care services are available for children diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The aims of the study are to: describe the palliative care services offered by the public health sector to children diagnosed with AIDS; describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS; describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided. This chapter captures a review on relevant published data in terms of palliative care in HIV and AIDS management and issues relating to palliative care provision for children.

2.2 HIV and AIDS

HIV is from a family of viruses known as retroviruses (Zimbabwe MOH&CW, 2007). The virus attacks the white blood cells which protects the body from illness. Over time the body's ability to fight common infections is weakened, opportunistic infections occur leading to AIDS. There are ways a person can get infected with HIV, such as through unprotected sexual intercourse, from an infected mother during pregnancy, during labour, at delivery or through breast feeding and with contact with infected blood or blood products through cuts in the skin or blood transfusion.

AIDS is a collection of signs and symptoms which show a person infected with HIV is very sick and has many infections at the same time. The body is weakened by HIV and is no longer immune or able to protect itself from infections (Zimbabwe MOH&CW, 2007).

African Network for the Care of Children Affected by AIDS (2006) indicated that there are differences between the disease progression in children and in adults. This is largely due to lower efficiency of the child's immature immune system which later develops. This difference results in much more rapid disease progression in children.

HIV medical interventions include treatment for opportunistic infections and AIDS-related cancers, primary and secondary prophylaxis for opportunistic infections and highly active antiretroviral therapy (Gwyther *et al.*, 2006). Gwyther *et al.* (2006) further noted that while HIV can affect any organ of the body, skin diseases, malnutrition, diarrhoea, respiratory tract diseases, and fevers are the major causes of symptoms, distress, and mortality in children.

These symptoms are distressing for the children and carers. Palliative care can enhance symptom management, adherence, and quality of life for children undergoing ART.

Gwyther *et al.* (2006) highlighted that HIV therapies affect quality of life. Numerous pills, food restrictions, side effects, toxicities, drug-drug interactions, and complex regimens are aspects of HIV therapy that affect the quality of life for adults and children affected and infected by HIV. Improving the quality of life is a key facet of comprehensive palliative care.

2.3 Palliative Care

2.3.1 General definition

Sepulveda, Marlin, Yoshida and Ullrich (2002) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem 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 (2007a) describes quality of life as the provision of pain relief and management of other distressing and debilitating symptoms. Quality of life dimensions of palliative care are achieved when patients' physical, psychological and spiritual needs are managed from diagnosis as well as the families' social, psychological and spiritual needs. The providers of palliative care also require psychological and spiritual support as they can develop stress associated with caring for dying patients and their families. Support is needed to assist them to cope with work related to loss, grief and change.

2.3.2 Palliative care in children

Palliative care for children is a special field closely related to that of adults and it applies the principles of other long term conditions in children. The World Health Organisation (1998) definition of palliative care for children and their families applies the following principles which also apply to other paediatric chronic disorders. These include:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- Palliative care begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes (WHO, 1998:8). The children's home refers to the child's own home, community home or institution.

It optimizes the quality of life for children living with life threatening illness such as HIV/AIDS through the active anticipation, prevention, and treatment of pain, symptoms and suffering. It requires an interdisciplinary team of health professionals and non-professional staff working together for the benefit of the child and his/her family. In light of HIV and AIDS palliative care is an essential component of a comprehensive package due to variety of symptoms that can be experienced such as diarrhoea, pain, cough and fatigue.

Richter (2008) states that providing any form of care that includes palliative care for children in the home is ideal as the child remains in a familiar environment with close people around. Other delivery sites are useful for support. Holloway and Seaton (2003) established that the experience in other countries such as India home based palliative care is possible with adequate planning and skills sharing.

While the principles of palliative care for children are the same as for adults, that is holistic, patient centred care that aims at quality of life, children also have special needs.

2.3.3 Palliative Care and HIV and AIDS

WHO *et al.* (2008) reported that palliative care is universally recognized as an essential component of HIV treatment and continuum of care, and yet UNAIDS (2007) acknowledges that palliative care is one of the most neglected aspects of healthcare. The benefits of palliative care in supporting people living with HIV have a strong evidence base and are recognized around the world.

WHO *et al.* (2008) further reported that palliative care supports treatment adherence as it is delivered alongside treatment from the point of diagnosis. This is mainly so as there is a high prevalence of pain and symptoms throughout the disease trajectory which needs to be managed and controlled.

2.3.4 Challenges in providing palliative care

Wright and Clark (2004) established that palliative care is a relatively new concept in many African countries and further reported that although Zimbabwe was the first country in Africa to start palliative care services, it still faces the same challenges that are being faced elsewhere in Africa. Kvalsvig, Chhagan and Taylor (2007) identified a number of challenges to providing palliative care which include: a few programmes providing palliative care for children in Africa, poor understanding of paediatric palliative care, few training courses resulting in limited qualified health professionals in paediatric palliative care in Africa, little African literature on children and palliative care programmes for children are developed in isolation.

2.3.5 Palliative Care versus Home Based Care

WHO (2002) refers palliative care to a type (concept) of care and central to this concept is the belief that everyone has a right to be treated and to die with dignity and that the relief of pain – physical, emotional, spiritual and social - is essential to the process. It may include a wide range of services to improve the quality of life for individuals and families through the alleviation of pain, symptom management and addressing physical, emotional, social and spiritual needs. WHO (2002) further indicated that palliative care services are not specific to any one setting or location. Palliative care is provided as a continuum of services across a network of providers including home based care, outpatient, hospital and hospice providers. Palliative care is generally grouped into four categories: clinical, psychological, social and spiritual (Sepulveda *et al.*, 2002).

Home based care programmes are a method (or vehicle) for delivering various types of HIV and AIDS services including palliative care. Doyle, Hanks and Macdonald (2003) established that home based care plays a significant role in providing access to palliative care, especially in poor resource settings. Many home based care programmes are missing the key components of palliative care such as pain and symptom control, prevention and treatment of opportunistic infections that are common with HIV and AIDS, emotional care and bereavement counselling.

2.3.6 HIV and AIDS and Home Based Care in Zimbabwe

Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) (2005) established that the impact of HIV and AIDS upon families in Zimbabwe has heightened the need for quality home based care. Surveys revealed that while significant efforts are being made through programmes specifically designed for the care and support of children, the integration of

programming for Orphans and Vulnerable Children (OVC), including those children living with HIV, within home based care initiatives is still low.

Too often, services for children are implemented as separate programmes, even within the same organization or the same household. HOSPAZ (2005), through a survey done in 2005 among its members throughout the country established that lack of skills and knowledge accounted for this situation. Comprehensive palliative care for children, which aims at improving the quality of life by providing physical, psychological, spiritual and social care, has been lacking.

2.4 Palliative Care Needs in HIV and AIDS in Children

2.4.1 Pain management in AIDS

Pain is defined as an unpleasant sensory and emotional experience associated with potential or actual tissue damage or described in terms of such damage (International Association for the Study of Pain, 1994). It is complex because it stems from several factors that include physical, emotional, social, spiritual and cultural problems. This is referred to as "Total Pain". It is subjective and therefore pain is "what the patient says hurts". Pain is one of the most common symptoms in palliative care and should be the 5th vital sign after blood pressure, pulse, temperature and respiration. It is usually under treated resulting in unnecessary suffering.

Hospice Africa Uganda (2006) confirmed that several studies have revealed that patients with AIDS often have more than one pain at any given time. Children are no exception as they too experience pain. Pain is what the child says hurts and it is different for each child. It can mean physical or emotional suffering. In palliative care pain is looked at as total pain that includes all kinds of pain that can be in the body and mind. The children cannot always articulate their experience of pain, therefore they need adults to recognize and respond to their pain. Children often do not complain and at times are mistaken to mean that they do not experience pain.

Hospice Africa Uganda (2006) highlighted that assessing pain in children poses great challenges due to language barrier, for example, some children may not be able to articulate their pain. In palliative care this requires pain assessment skills at each developmental age. Pain assessment also requires special skills in communication at different ages and stages of development and a flexible approach which is unique to each child. Furthermore, great attention has to be paid when assessing symptoms in children as they cannot always tell what is distressing them.

The WHO (1998) three step analgesic ladder outlines the proven stepwise approach which should be used in managing physical pain. Medication is prescribed based on the pain severity, moving up the steps of the ladder from weak medicines to stronger analgesics, as the pain increases in intensity. The ladder represents a model that begins with mild analgesics and progresses to stronger analgesics for persistent or increasing pain. Other medicines such as analgesic adjuvants can be used in combination at any level of the ladder.

2.4.2 Symptom management in HIV and AIDS

"Symptom treatment in children has not been systematically assessed, so what is currently used comes from the adult literature. Yet, children are not small scale adults, nor are they a uniform group." (Bruera, De Lima, Wenk and Farr, 2004:231). Gwyther, Merriman and Mpanga (2006) established that the trajectory of illness in HIV and AIDS disease development is different to that of cancer, as it is far less predictable. For example, patients including children are predisposed to opportunistic infections and some cancers such as kaposi sarcoma. AIDS has always presented unique and psychosocial problems for patients, families and those providing the care. In palliative care it is essential that all reversible and treatable conditions relating to HIV and AIDS are accurately assessed and diagnosed. These should be actively treated whenever possible if quality of care is to be achieved (Gwyther *et al.*, 2006).

Twycross (2003) states that palliative care extends far beyond physical symptom relief; it is often referred to as holistic care as it seeks to integrate physical, emotional, social and spiritual aspects of care that is needed by patients and families facing life-threatening illness and bereavement. It is best provided by a multidisciplinary team and is a partnership between the patient, the family and the caring team. Palliative care focuses on quality of care and Twycross (2003) further highlighted that the ethics of palliative care are those of medicine in general and guided by four cardinal principles; respect for patient autonomy (patient choice), beneficence (do good), non-maleficence (minimize harm) and justice (fair use of available resources).

Harding and Higginson (2005) highlighted that antiretrovirals which are the medicines that are given to prolong the quality of life for people living with HIV and AIDS, are also associated with high symptom prevalence. Through the provision of palliative care these can be controlled. AIDS continues to be a life-threatening illness as many people do not have access to antiretroviral therapy.

Antiretroviral therapy is the correct provision of ARVs with adherence support and all the appropriate care that includes several components such as nutrition, counselling, treatment of opportunistic infections and infection control. Palliative care is then the only option and can be provided even at end of life.

Harding, Norwood, Leake-Date, Fisher, Edwards, Arthur, Anderson and Johnson (2007) established that as palliative care is being delivered in the community, it gives palliative care team the opportunity to provide information on HIV prevention. Issues such as counselling and testing can be strengthened.

Harding *et al.* (2007) further reported that a child with HIV is faced with overwhelming physical needs, such as pain and symptom management. In the absence of the treatment with ART, the child becomes progressively weaker as the immune system and other parts of the body are affected. The child is susceptible to opportunistic infections. The symptoms of these infections and conditions are commonly painful and debilitating and affect the quality of life. In the event that the children are treated with ART, they may still become sick and continue to need palliative care. There is however still limited access to ARVs in developing countries that includes Zimbabwe.

2.4.3 Psychosocial support for children affected by AIDS

The term "psychosocial support" has been mystified as something very technical that can only be done by people who have received training. However, the term is not new but has always been addressed by society and needs to be strengthened. The Regional Psychosocial Support Initiative (2007) defines psychosocial support as "an ongoing process of meeting the emotional, social, mental, spiritual and physical needs of a child. This is done through ongoing care and contact with the child" (Regional Psychosocial Support Initiative, 2007:7).

The term psychosocial can be broken down into three parts and these are:

- **Psycho:** this refers to anything that involves what an individual feels, thinks and their emotions.
- **Social:** this refers to the community in which the individual lives and the various players that have contact with them. These include relatives, teachers, classmates, friends, church members and neighbours.
- **Support:** this refers to how an individual is assisted by the people indicated under the social sub point to face challenges that affect their emotions, feeling and thoughts.

Enhancing Care Initiative (ECI) (2004) highlighted that all children have physical, emotional, social and intellectual needs that must be met if they are to enjoy life and develop to their full potential. HIV and AIDS often lead to a number of psychological and social problems, such as anxiety and orphan-hood. It is imperative that children and their families are supported during illness and bereavement.

Support for children can be achieved through counselling, support groups and other support systems in the community. Marston *et al.* (2006) highlighted that children require extra support to gain their sense of security. Children need help to find ways to express their feelings. Bereavement counselling and peer support groups give children the opportunity to express their feelings and to talk with others in similar situations. World Palliative Care Alliance (2008) emphasize that emotional support is a crucial component of palliative care for children. Children need to be involved in play if they can. Activities such as drawing, music, watching others play and involvement in family and community life are very helpful. Children who are sick or bereaved also need to have their questions explored.

Nasaba, Defilippi, Marston and Musisi (2006) indicated that HIV/AIDS is often associated with profound psychological distress that must be addressed at all stages of HIV infection. Psychological support is critical for helping children, individuals, couples, families and friends affected by HIV cope with their fears and emotions. Such support has been known to improve understanding and acceptance of illness brought about by HIV infection.

The children clinically diagnosed with AIDS have significant emotional needs. They face tremendous emotional challenges as a result of their own diagnosis, when a child should be playing and enjoying childhood, he/she faces recurrent illnesses, fear of the future and stigma and discrimination. Some of the emotional pain is caused by social challenges that include; not properly cared for as parents might be sick too, poor access to health services, inadequate nutrition, living in poverty, unable to attend school and unable to interact and play with peers (Enhancing Care Initiative, 2004). Children who are clinically diagnosed with AIDS are often grieving for the loss of their own good health, which may be in addition to the loss of parents, siblings and their peers (Marston *et al.*, 2006).

UNICEF (2006) established that while many programmes are being implemented to address the "physical needs" of orphans and vulnerable children, little attention is being given to the psychosocial needs of these children. The survey on Orphans and Vulnerable (OVC) children carried out by UNICEF (2004) noted that only 1% of assistance to OVC was in emotional and psychological support. This was also supported by a study done in Manicaland in Chimanimani district in Zimbabwe which noted that less than 5% of assistance

to both the OVC and chronically ill was emotional and psychosocial support (Zimbabwe MOH&CW, 2005). Adults and caregivers lack the skills of dealing with care and bereavement support for children.

2.4.4 Spiritual support for children affected by AIDS

Gwyther *et al.* (2006) highlighted that support around spiritual issues is important to a child's well-being as much as physical and emotional support. With life-threatening illness common spiritual questions that arise from the child and the family are: is there life after death? What happens when we die? Does God still love me? Am I being punished? Why me? The perplexing questions that are not easily answered can cause serious distress. That distress can manifest itself in physical and emotional pain. Allowing children to do storytelling, drama, pray, poem or sing and worship offers spiritual renewal and support. Recreation, sports, and arts activities allow children to play and learn. Children and families can find comfort and support in doing memory work together that holds special memories about the family.

2.4.5 Bereavement care in children

Marston *et al.* (2006) reported that due to HIV and AIDS children are living with multiple and ongoing losses leading to hopelessness and psychological effects. Marston *et al.* (2006) established that adults are not comfortable with speaking of death and dying with children. Children who are sick may be aware that they are dying and that something is wrong with them. Children's understanding of death and dying changes as they grow older. Children can begin to feel grief as soon as they understand that they or their loved ones are going to die. Therefore, bereavement work should start as soon as children are diagnosed with a terminal illness. There are many ways that can help the children and families before, during and after the bereavement such as encouraging talking and communication (Marston *et al.*, 2006).

2.4.6 Developmental needs

Marston *et al.* (2006) indicated that palliative care for children must be delivered in line with developmental stages and changes with the ability to assess and manage pain and other distressing symptoms. The developmental stages relate to how children respond to situations at different times of their growth, how they communicate and their understanding of situations such as death. Examples of developmental stage are as reflected in Table 2.1.

Table 2.1 Age-related responses to death

Age of child	Age-related responses to death
0-3 years	Children are not able to talk about grief and may only express it physically Crying and regressive behaviour
3-5 years	Understanding is more than what is verbalized Feelings that God is very real
6-12 years	They have the ability to understand the causes of death Are able to communicate in a logical manner
Adolescents	They understand that death is irreversible and that it is final. They are also facing life crisis of transition to adulthood

(Adapted from Marston et al., 2006:413)

In Africa the dominant social and economic context for children with HIV infection is one of poverty, with attendant nutritional deficits and poorly developed health and education services. In these circumstances the developmental risks to the children are many due to frequent illness and lack of developmental stimulation if child is also HIV infected.

2.4.7 Communication issues

Nasaba *et al.* (2006) highlighted that children need to be included in discussions relating to sickness and death. Nasaba *et al.* (2006) further discussed the fact that in many cultures children are not included in discussions - the "seen not heard" concept which poses a huge challenge in providing palliative care to children. In order to allay their anxiety children are supposed to be given honest and correct information. Talking with children allows them to express their fears, sadness and to ask questions. Communicating and talking with children sometimes exposes adults to dealing and answering difficult questions that the children might have.

2.4.8 Children and access to care and treatment

Hospice Africa Uganda (2006) highlighted that ARVs inhibit the replication of the HIV virus in the body and helps with the reconstitution of the immune system in many patients, thereby reducing the risk of opportunistic infections. It also reduces the progression of the HIV infection to AIDS. Hospice Africa Uganda (2006) further indicated that ART is a comprehensive approach that encompasses several components including the course of medication used to help adults and children living with HIV and AIDS to fight the growth of

HIV in their bodies so that the person can stay healthy. Therefore ART is the correct provision, as a total package, of ARVs with adherence support and all the appropriate care such as nutrition, infection control, treatment of opportunistic infections as well as testing and counselling. Mpanga (2006) established that ART has ushered a changing focus of care from end of life care to living with HIV as a chronic disease or positive living during which time effective palliative care services are required.

WHO *et al.* (2008) emphasizes that palliative care should be given to all people who need it. Further, initial and periodic community needs assessment and planning contribute to the development and implementation of hospice and palliative care services, with special attention to securing access for the underserved including people living with HIV/AIDS and children. However, children living with HIV have less access to treatment than adults in the same setting. In 2007, about 8% of infants in low middle income countries were tested within two months of their birth (UNAIDS, WHO, 2008). Access to palliative care for children requires adults to allow children to participate in decisions that affect their health.

WHO *et al.* (2008) further indicated that the provision of a comprehensive care and support for children requires inter-departmental and multi-disciplinary programmes. Experiences have shown that the success of paediatric ART needs linkages with other services such as TB clinics, nutrition centres, family planning clinics and the community has to be a priority to ensure appropriate referrals and the continuum of care. Caregivers are the entry point into the community, they need training for them to help the children on ART and refer when appropriate (WHO, 2007).

2.4.9 Rights of Children in palliative care provision

The UN Convention on the Rights of the Child (1989) and the Organization of African Unity (OAU), African Charter on the Rights and Welfare of the Child (1990) makes advocacy for children an obligation for health professionals. As palliative care is provided to children, care and support is in the best interest of the children. According to Nasaba *et al.* (2006) the following principles should be adhered to when providing palliative care to children:

- Non-discrimination between children means that children with HIV and AIDS should not be discriminated against.
- Openness and truth; most children prefer to know the truth and view disclosure of their illness positively.
- Preparing children and parents for impending death refers to discussing children's illness with them as it helps them to overcome their fears and worries.

- Recognising the individuality of children means that health professionals acknowledge that children respond to illness and death differently.
- Participation and involvement of children means that children should be included in making decision in matters that concern their health. Palliative encourages parents and carers of the children to include them in discussions relating to their illness.

2.5 Support for parents and carers of children affected by HIV and AIDS

2.5.1 Emotional support for families and carers of children affected by HIV and AIDS

Olson, Knight and Foster (2008) highlighted that looking after a child diagnosed with AIDS is very challenging for families. Supporting the family will also benefit the child that is sick. Families require a lot of encouragement and understanding as they care for the sick child. At times parents are ashamed to ask for help when faced with a sick child. Parents and other carers need advice and support to assist them to make decisions which will safeguard the health of the children and meet emotional security. This support is also extended to young carers who need constant encouragement. The young carers need to be helped to become confident as they provide care, be involved in decisions about the sick family member and be free to seek help when required.

2.5.2 Spiritual Support for parents and carers of children affected by HIV and AIDS

Nasaba *et al.* (2006) highlighted that parents naturally have many spiritual questions when they have a child who is facing a life-threatening illness. Guilt feelings and blame are usually felt. Parents are often angry and may try to impose their beliefs to make sense of their experience. They need support and guidance on their journey of understanding. Working with dying and bereaved children may be a very stressful and difficult work for families, carers and health workers, as it may make them think about their own beliefs and personal fears. It is important for carers to have their own source of spiritual strength. Help is offered through listening as the family tries to make sense of what is happening.

2.6 Conceptual Framework

Maslow (1970) proposed that there is a hierarchy of needs that arise from the basic biological needs. The needs at one level of the hierarchy must be satisfied before proceeding to the next level. The needs that constitute Maslow's hierarchy are as follows; biological needs, safety needs, belongingness and love needs, esteem needs, cognitive needs, aesthetic needs and self-actualisation. Maslow's basic needs include food, water, sleep, health, shelter among others (Mataruse and Mwatengahama, 2001).

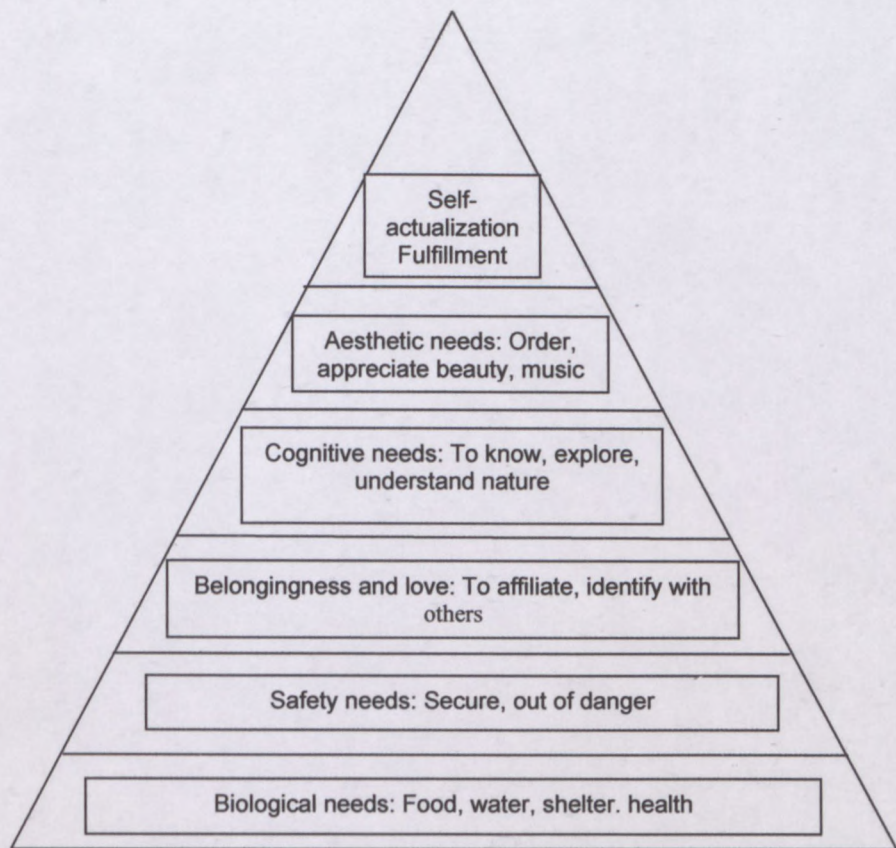


Figure 2.1: Maslow's hierarchy of needs

(Adapted from Maslow 1970)

2.7 Measuring palliative care services

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychological, social and spiritual (WHO, 2002). It is from this definition that five key areas of palliative care have been identified for measurement: pain and symptom relief; access to drugs; emotional, spiritual support and grief counselling; support for family carers; and family-based advanced care planning (Hearn & Higginson, 1999). Another tool was developed by the Monitoring and Evaluation Reference Group focusing on patient-level indicators in order to measure the quality of palliative care within the African setting (African Palliative Care Association, 2006). Five key domains were identified against which potential indicators were developed to measure palliative care. These five domains are physical; emotional; spiritual; information received and family support. Improved quality palliative care services for patients and families including children are measured by the following indicators:

- Pain and symptoms are relieved
- Have access to essential palliative care drugs including opioids
- Emotional and spiritual support and grief counselling provided

- Support for family caregivers taking care of a patient at home
- Increased proportion of families receiving support for planning for the future

The above indicators are measured using the African Palliative Care Association African Palliative Outcome Scale (2006) and the Palliative Care Indicator Guide (Hearn & Higginson, 1999). The two indicator guides were used as they each complement the other.

2.8 Summary

Chapter two focused on published literature and health policy regarding paediatric palliative care and related issues, with specific focus on the impact of HIV pandemic on children in Zimbabwe. It also highlighted challenges in providing palliative care for children in Africa such as few programmes providing palliative care for children in Africa. In chapter three, the research methodology used for this study was discussed.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

In chapter two the literature review revealed what constitutes palliative care such as physical, spiritual, emotional and social needs of children. The challenges to providing palliative care for children were highlighted. Many children do not have access to palliative care as compared to adults. In this chapter the research methodology will be presented.

3.2 Research Methodology

3.2.1 Research design

The research design is primarily qualitative with a quantitative component. Qualitative methods focus on the aspect of meaning, experience, and understanding. Qualitative approach to research refers to research that analyses narrative information in an organised, but intuitive fashion (Brink, 2006). Whereas, quantitative research methods focus on numerical information that is analysed through statistical procedures, uses structured procedures and formal instruments to collect information (Brink, 2006). The research strategy is descriptive and comparative. Borg (1989) noted that by using the descriptive survey design, it will be possible for the investigator to gather systemic empirical data that can be analyzed, interpreted and used as basis for carrying out the study. Using a descriptive and exploratory strategy provided answers to what palliative care services are available to children diagnosed with AIDS in Harare, what the palliative care needs of the children were, as well as if the needs of the children were provided for by means of the available services. The researcher used the informant approach by collecting the information concerning the needs and palliative care services provided for children diagnosed with AIDS, from key informants who are presumed to be in a position of knowledge.

3.2.2 Context of the study

The study was conducted in the public health sector and in three selected NGOs that provided palliative care for children in urban and close-by areas of Harare, Zimbabwe. The public health sector provides its services at clinics, district hospitals, provincial hospitals and central or tertiary hospitals. The services are graded in levels of one to four and one being clinics in the rural areas and four are tertiary hospitals (refer figure 1:2).

The NGOs were selected based on their services that included palliative care for children diagnosed with AIDS and were readily assessable to the investigator. The three organisations also provided home based care for children through home care teams.

The differences between these NGOs were that one organisation was a faith-based organisation and had an in-patient unit for very sick patients both adults and children. It also served as a place of respite for those who had no one to take care of them at home. This facility offered a home based care programme that was linked to the in-patients unit, to provide palliative care and follow-up support at home for those who would have been discharged from the in-patient unit. The other two NGOs provided purely home based care without any in-patient facility. Among the other two organisations, one was situated in the peri-urban area of Harare, an area that was in the vicinity of Harare which provided an opportunity for clients who lived in the outskirts of Harare to receive palliative care, while the other organisation, was situated in the heart of a high-density suburb of Harare.

3.3 Study population

Entiwhistle and Nisbet (1970:24) define population as “any group of people or observations or test items in which we happen to be interested”. The study population for this study was senior health officials from the Ministry of Health and Child Welfare, senior personnel from the selected NGOs; and children whose parents/legal guardians consented to them participating in the study were included in the study population. The children were receiving care from the NGOs.

3.3.1 Ministry of Health and Child Welfare Officials

The study population from the Ministry of Health was made up of three senior health officials that included two consultant paediatricians. The three officials worked closely with the AIDS and Tuberculosis (TB) Unit that manage issues related to HIV, AIDS and TB in Zimbabwe. The unit was managed by senior health officials whose responsibility was for AIDS and TB prevention as well as treatment, care and support of adults and children infected and affected by AIDS and TB. The study informants were also policy makers in the Ministry of Health and Child Welfare and therefore very important in this study.

3.3.2 Selected NGOs

The senior managers from the three selected NGOs formed part of the target study population. In terms of the NGO sector, these organisations were selected based on their services that included palliative care for children diagnosed with AIDS. The organisations

were known to the investigator to provide palliative care and home based care for children through home care teams.

3.3.3 Children diagnosed with AIDS

Children diagnosed with AIDS, and their parents/legal guardians or main carers who consented and willing to voluntarily participate in the study were included in the study population. In terms of AIDS diagnosed children, these were children who were receiving care from the three selected NGOs.

3.4 Sampling of study participants

Brink (2006:124) states that sampling "refers to the researcher's process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest". A sample is a subset of the target population selected to participate in the study (Brink, 2006). The sampling procedures for the Ministry of Health and Child Welfare officials, selected NGO managers and the children, whose parents/legal guardians or main carer consented to participating in the study, are discussed per section of the study population included.

3.4.1 Sampling: Ministry of Health and Child Welfare

Robson (1993:143) states that purposive selection in research is "the principle of selection in purposive sampling is the researchers' judgement as to typicality or interest". Purposive sampling which is also referred to as theoretical sampling was applied to sample the key informants for the structured interviews (Annexure 6) in the Ministry of Health and Child Welfare. Purposive sampling was applied in order to identify the right participants with the required information and knowledge of services in place for children clinically diagnosed with AIDS in Zimbabwe. Brink (2006) states that purposive sampling is one of the techniques of non-random sampling based in qualitative research methods. The technique was applied based on the investigator's judgment; therefore it was appropriate to apply purposive sampling, as only the participants who could provide with the information required from the public health sector were needed. The sample was made up of three health officials that included two paediatricians.

3.4.2 Sampling: Selected NGOs

Purposive sampling was applied based on the researcher's judgement to select the NGOs that were providing palliative care for children diagnosed with AIDS. A total of five people from the three NGOs participated in the study as they were able to provide the required

information and communicated well in English. Two of the NGOs opted to have two people in managerial positions interviewed together so they could help each other with the information required.

3.4.3 Sampling: Children diagnosed with AIDS

Convenience sampling method which is also referred to as accidental or availability sampling was applied to select the children for the study (Brink, 2006). This was based on the readily available participants from the selected NGOs. Sampling of the children at the faith based organisation was conducted at the in-patient unit, while home visits were made to children who were in the home based care programme of the other two NGOs.

Inclusion and exclusion criteria of the study participants were dependant on the children diagnosed with AIDS and parents/legal guardians or main carer who consented and were willing to voluntarily participate in the study. The availability of the children at the time the researcher visited or collected the data also met the inclusion criteria. The inclusion and exclusion criteria of these children were also based on WHO presumptive clinical diagnosis guidelines (Annexure 11), where virological tests are not available. The children of parents/legal guardians or main carer who declined giving informed consent were excluded from participating in the study without compromising them from receiving standard care. Another inclusion criteria was that the children provided assent to participate. Assent is when a minor child gives an affirmative agreement to participate after information has been given to the child in a language he or she understands.

The number of participants to be included was not determined in advance by the investigator; hence the number of children interviewed depended on data saturation (Brink, 2006). Brink (2006) states that data saturation is the point at which new data no longer emerge during the data collection process. Sampling continued until the point of data saturation where there was no new information coming from the participants. The sample was twenty-two children diagnosed with AIDS.

3.5 Ethical Considerations

The principles of research, such as respect for persons, beneficence (do good), non-maleficence (minimise harm), justice, informed consent, confidentiality and anonymity (Brink, 2006) were applied during this study.

Informed consent refers to an agreement with or permission from a person after they have understood clearly what the decision to participate in the study means. In research it was

based on an understanding of the possible harm and risk of participation in a study, after adequate information had been given.

The collected data from the study participants was kept by the investigator in a safe locked up cupboard, where no other person had access.

3.5.1 Cape Peninsula University of Technology, Health and Wellness Sciences Research Ethics Committee and Medical Research Council, Zimbabwe

The Faculty Research Ethics Committee granted permission to conduct the study (Annexure 2) and Zimbabwe Medical Research Council (Annexure 3.1) and (Annexure 3.3). An extension was also granted to the researcher by the Medical Research Council of Zimbabwe to continue conducting the research till May 2009 (Annexure 3.4).

Ethical issues relating to both sectors involved in this study were discussed in detail in the next section.

3.5.2 Ethical issues: Ministry of Health and Child Welfare and Selected NGOs

Informed consent was obtained from the study participants from the Ministry of Health and Child Welfare and selected NGOs. The process of obtaining informed consent was done to ensure that the participating individuals did so willingly and with adequate understanding. Informed consent refers to an agreement with or permission from a person after they have understood clearly what the decision means (Schenk & Williamson, 2005). In research informed consent is based on an understanding of the possible harm and risk of participation in a study, after adequate information has been given (Mason and Mielke, 2003).

The study participants were also assured that the information given to the researcher would be kept confidential. Confidentiality is a condition under which the information revealed by an individual participant in a relationship of trust will not be disclosed to others without permission (Schenk & Williamson, 2005). The study participants were informed that they had the right to withdraw from participating in the study should they wish to do so, without any form of victimisation.

Confidentiality of all information obtained during the research process rested with the principal researcher. During data analysis anonymity was assured by allocation of a unique number to each respondent, rather than a traceable name/reference. They were further given a detailed explanation of how collected information would be handled such as coding system so that the information given could not be traced back to identify any participants, other than

by the investigator. The purpose of the study was explained fully by the investigator, emphasizing its academic importance and relevance to the care of children.

3.6 Ethics and children

3.6.1 General key ethical considerations

Schen and Williamson (2005) state that there are three basic ethical principles whose implications rise above all geographic, cultural, economic, legal and political boundaries. These are respect for persons including children, beneficence and justice. "Strict observance of these responsibilities addresses the differences in power between participant and investigator that leaves the child or adolescent vulnerable to exploitation" (Schen and Williamson, 2005: 3)

3.6.2 Respect for persons

This requires respect for a person's life, health, privacy and dignity. Respect for autonomy was also given and recognising that the person giving consent had to be treated with respect for being able to make that personal choice and empowering him/her to make rationale and reasoned decision. According to Brink (2006) individuals with diminished autonomy require protection, and this group includes children, the mentally impaired, unconscious patients and patients who are institutionalised.

3.6.3 Beneficence

In carrying out the research potential harms and discomforts are minimised and potential benefits are maximised. The welfare of the study participants was safeguarded from risks and harms that could be physical, emotional, social, spiritual and cultural. However Brink (2006) states that qualitative research risks exploring unresolved issues that could be painful and cause discomfort to the patients. The researcher was aware of these and acted in a manner that reduced risks and harm to the children.

3.6.4 Justice

Justice refers to fair selection, treatment of the participants and their right to privacy. Each child was treated in accordance with what was right and proper for the participants. One of the sub-division of justice is the context of distributive justice, requiring the equitable distribution of burdens and benefits on the participants. The researcher used the concept of justice in selecting the study participants, as this was done in relation to the aim of the study

and not simply because of their availability, their compromised health position or their vulnerability.

3.6.5 Children's participation

Since the research involved children, special considerations were made to safeguard the rights of these children, such as.

- Right to protection from all forms of maltreatment before, during and after the research;
- Right to participate and express his/her opinion freely in matters that concern them.

Schen and Williamson (2005) highlighted that children's participation helps improve methods for gathering information, thus enhancing the accuracy and usefulness of the research findings. Mason and Mielke (2003) stated that it is unethical to prevent children from participating in decision-making about things that affect their lives. Children can provide crucial information about their needs and involving children in age-appropriate decision making have benefits such as, providing opportunities to improve their self-esteem and support for each other (Schen and Williamson, 2005).

In many instances in Zimbabwe, households are headed by children in the absence of an adult parent who would have died of AIDS (UNICEF, 2006). Research efforts should pay particular attention to the needs of these groups in order to reduce their vulnerability and also to protect them from exploitation. Schen and Williamson (2005) stated that children who are in especially vulnerable situations require additional safeguards to protect their welfare. This can be done through involving local community and stakeholders by explaining fully the purpose of the study and benefits to both the children and the community. The community can give permission if the activity or research study is acceptable. Schen and Williamson (2005) also indicated that the community can advise on culture and gender considerations. The researcher managed this through seeking permission from Ministry of Health and Child Welfare, Medical Research Council of Zimbabwe, selected organisations acceptable and working in the community, the parents/guardians or main carers and the children themselves. Data from the children was collected in the presence of the parent/guardian or main carer and a representative from the selected organisations.

3.6.6 Children's ability to say no

The researcher assured the children that they did not have to answer or talk about anything they did not want to. Their decision did not affect their ability to receive care at any time now and in the future. However the researcher highlighted that it would be appreciated if the

children could give honest and open answers, so that the researcher could find out their needs.

3.6.7 Informed Consent and Assent

Schen and Williamson (2005) stated that parents/guardians are regarded as the best protector of the interest of minor children. The researcher ensured that the parents/guardians or main carers participated willingly and with adequate understanding. The active agreement or the child's assent was obtained. The researcher was sensitive to the children's developmental stages and understanding. While this was done, the children could stop the interview at any time and refuse to answer any questions if they chose to and have no effect on their care. The best interests for the children were used as a primary consideration. The researchers acted in the best interest of the children at all times, the children were protected and legal and ethical principles were upheld (Zimbabwe MOH&CW, 2008).

3.6.8 Anonymity and Confidentiality

The principles of anonymity and confidentiality were applied to shield the children from negative consequences that could result from their participation. Anonymity refers to the condition under which the identity of a participant is not collected and cannot be traced back from the information collected. The names of the children were not collected by the researcher. Use of numbers and a coding system was applied. The children were also assured that the information they would give in a trusting relationship is not disclosed to others without their permission (Mason and Mielke, 2003). Confidentiality was maintained. The researcher guaranteed the safety and security of the children who participated in this research study.

3.6.9 Age of consent in Zimbabwe

In Zimbabwe a child is any person under the age of 18 years, however in issues of HIV pre-test counselling and testing, children aged 16 years old and above are able to give an informed consent for pre-test counselling and HIV test (Zimbabwe MOH&CW, 2005b). For children who were below 18 years old a parent/legal guardian or main carer gave the consent, on behalf of the child. Written informed consent was obtained from parent/legal guardian or main carer. The researcher is fluent in English and Shona languages. The parent/legal guardian or main carer was informed that he/she had the right to withdraw from participating in the study at any time and any withdrawal did not affect in any way the standard care and benefit due to them.

Under no circumstance were the children forced to participate against their will even if their parents/legal guardians or main carer approved participation. No children were victimized for non-participation. Rather in cases where the researcher would consider that care was compromised, the researcher undertook to ensure an opportunity for referral and linking to appropriate care provider was created.

In order to protect the child, he/she was given an opportunity to be involved in decision making as far as taking part in the study, after adequate information regarding the study had been explained fully in a way the child could understand. This is termed assent when a child gives an affirmative agreement as highlighted in the children section below.

3.6.10 Ethical issues: Children diagnosed with AIDS

The researcher recognised that children are a vulnerable population in the research and health care. This research was undertaken with this understanding in mind. It was important to get the children themselves to say what they perceived to be their needs when sick chronically. Information was obtained in a non-threatening way and being sensitive to their health status and the fact that they were minors. An open question was asked with no promises made. The child was asked in the presence of the parent/legal guardian, or main carer, care provider or the person in charge of the children at that particular time.

The parent/legal guardian or main carer was given the option to be present during data collection from the children. It also safeguarded the child knowing that the people responsible for his/her care were present. With the NGO manager being present it ensured that the needs that the child highlights could be addressed if at all possible without any delay. This ensured sensitivity towards the child's need. Written informed consent was obtained from the parents/legal guardians or main carer before any data was collected.

In addition, the researcher sought the agreement of the children or obtain assent, recognizing the child's age and maturity, to participate in the study before information was collected. Assent was obtained from the children because of their status as minors and their compromised health status. It was important for the children to assent. The researcher communicated with the children in a way children would follow or understand using simple explanation on what was involved, and gave the child an opportunity to either agree or disagree. Information was also given to the child that he/she had the right to refuse or answer any questions and that he/she could choose to or stop answering at any time and will still receive standard care without any restrictions. The children had a right to make their choice without being forced.

Since the research involved children, special considerations were made to safeguard the rights of these children, by providing both children and parents/legal guardians or main carer adequate information to enable them to make informed decision to participate or not, English (Annexure 4) and vernacular participant information sheet (Annexure 4.1).

Before data was collected the children and their families were assured of the following: that they were free to withdraw from the study at any stage, any withdrawal did not affect in any way the standard care and benefit due to them. Furthermore, they were assured that it would not affect the care they were receiving from the Home Based Care centres. According to Schenk and Williamson (2005), children have a right to protection from all forms of maltreatment before, during and after the research and to participate and express their opinion freely in matters that concern them.

However, data collection for the study from the children was undertaken through an open question guide, English (Annexure 8) and vernacular (Annexure 8.1) and observation in the presence of the manager and parent/legal guardian or main carer to ensure that the rights of the children who were already vulnerable due to illness were preserved. Informed consent was obtained from the children who were older and assent from the younger children depending on their developmental age. Sensitivity was practised on the children who were very sick and those that were from child headed households by not spending too much time with the children and ensuring the presence of someone who was familiar to the children.

Where children with specific requirements were identified, such as pain control, appropriate referral was recommended, and information given on where other support services were available. Explanations of the whole process was done in the language the participants understood best, that is vernacular (Shona), before informed consent was given by parent/legal guardian or main carer, and the children assented to taking part in the study. The researcher is fluent in both English and vernacular languages.

Involving the children was done in a sensitive manner, bearing in mind that conducting research in children would create an opportunity to have evidence based information that would be used to enhance quality of care for the children. Bypassing and not involving the children in research in the pretext of their vulnerability would be neglecting the children and refusing them evidence based care.

3.7 Data Collection

The data was collected from the Ministry of Health, selected NGOs and the children whose parents/legal guardians or main carers consented to participate in the study and were in turn

cared for by the selected organisations as described below. The children also gave an assent to participate in the study.

3.7.1 Data collection: Ministry of Health and Child Welfare

Data were collected from the Ministry of Health and Child Welfare by means of unstructured and semi-structured interviews using an interview schedule (Annexure 6). Unstructured interviews are free flowing and are conducted more like a normal conversation with a purpose. Unstructured interviews produce in-depth information (Brink, 2006). In semi-structured interviews the researcher asks a certain number of specific questions; however he/she can also use additional probes. Further, in semi-structured interviews both open-ended and closed-ended questions are used (Brink, 2006). The interview schedule was guided by the palliative care indicator guide (Annexure 9) and the African Palliative Care Association African Palliative POS (Annexure 10). The interview schedule is a questionnaire with closed-ended questionnaire that has indications of how to answer the questions.

The data collected enabled the researcher to describe the palliative care services rendered by the public health sector. The draft instruments were field tested to ensure validity and reliability of these instruments. Where validity relates to getting the required data that will answer the question and reliability that the same response will be elicited when questions are repeated to get the intended information. Data on the type of services offered to children clinically diagnosed with AIDS in the public health sector at Tertiary, Provincial and District level was collected. The data included what was available for pain management using WHO analgesic ladder, as well as symptoms management, provision of ART, counselling services available for emotional, spiritual and social issues, bereavement care, information sharing and food security. The other information obtained included systems that are in place for the continuity of care of children receiving palliative care, once discharged from hospital into the community and the challenges faced in the public health sector in implementing palliative care programmes for children in hospital and out of hospital.

Semi-structured and unstructured interview were conducted using unstructured and semi-structured interview schedule (Annexure 6) with the three key informants in the Ministry of Health and Child Welfare in order to establish the Public Health Sector services available for children with AIDS in Harare, Zimbabwe. The researcher collected information on palliative-specific services that the Public Health Sector provided for children clinically diagnosed with AIDS in Zimbabwe based on interviews with the key informants in the Ministry of Health and Child Welfare (Annexure 6).

The researcher introduced herself by name, the organisation she worked for and mentioned that she was conducting a study as part of a requirement towards obtaining masters degree in a nursing qualification. These interviews were conducted in English. The interviews took place in private offices at the office premises of the key informants to ensure confidentiality. Appointments were made in advance and the interviews lasted about forty-five minutes each.

The key informants were assured that their names were not to be revealed and under no circumstance were the information given, is traced back to her/him. No names would appear anywhere in the study document. The researcher used colour coding and numbers only known to the researcher to identify the informants. This ensured anonymity of the key informants. Confidentiality of all information obtained during the research process rested with the investigator. The study participants were also assured that the information given to the researcher would be kept confidential. Confidentiality is a condition under which the information revealed by an individual participant in a relationship of trust will not be disclosed to others without permission (Schenk & Williamson, 2005). The key informants were asked for permission to be interviewed. Permission was sought to tape record the structured interview and for the researcher to write notes. Where the respondent did not want to give an answer or responses it was shown by their being quiet or not giving responses to any questions asked. The researcher did not pressurise those participants to respond.

The researcher asked the key informants for permission to send the compiled notes for them to check whether the information had been captured correctly. It gave the key informants the opportunity to check accuracy of the information and for the key informants to fill in gaps if there were any in the verbatim transcript of these interviews. However, there were no gaps identified by the key informants.

3.7.2 Data collection: selected NGOs

Structured interviews were conducted using a structured interview schedule (Annexure 7). Structured interviews are formalised so that all respondents are asked the same questions (Brink, 2006). The interview schedule was guided by the palliative care indicator guide (Annexure 9) and African Palliative Care Association African Palliative POS (Annexure 10). The interview schedule is a questionnaire with closed-ended questionnaire that has indications of how to answer the questions. The data collected enabled the researcher to describe the palliative care services rendered by the NGO sector. The draft interview schedules were shared with the supervisors who gave input to further guide the development of the schedule. The schedules were then field tested to test whether it was clear and understandable and able to gather the intended information and ensure validity and

reliability. The schedule was used to collect the following information relating to palliative care services that the NGOs provided to children diagnosed with AIDS.

Structured interviews were conducted in English with senior managers of the selected NGOs in order to establish palliative care services they provided (Annexure 7). The researcher introduced herself by name, organisation she worked for and conveyed that she was conducting a study as part of her masters' degree programme. The overall purpose of the study is to determine what palliative care services are available for children diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The study participants were asked for permission to be interviewed. Permission was sought to tape record the interview and for the researcher to write notes. Where the respondent did not want to give an answer or responses it was shown by her/him being quiet or not giving responses to any questions asked. The researcher did not force participants to answer if they did not do so voluntarily.

The interviews were conducted in private offices of the NGO premises to ensure confidentiality. Appointments were made prior to the interviews which each lasted about forty-five minutes. The respondents were assured that his/her name was not be revealed and under no circumstance was the information given be traced back to her/him. No names appeared anywhere in the study document. The study participants were also assured that the information given to the researcher would be kept confidential. The researcher asked the respondent for permission to send the typed manuscript of the interviews for her/him to check whether the information had been captured correctly. It gave the respondent the opportunity to check accuracy of the information and for the respondent to fill in gaps if there were any. There were no gaps that were identified in manuscripts by the study informants.

The data collected from the selected organisations was on staff complement; understanding of palliative care for children, components of palliative care provided for children, pain and symptom management, counselling, bereavement care, family support, information shared with others, food security, provision of ART as well as play and education. The other information obtained was on the activities that were done to integrate palliative care for children into home based care, how children or families access services from the organisations; challenges faced in implementing palliative care programmes for children and the number of children that were in care.

The researcher conducted the interviews in person and administered the questionnaires and filled in the responses from the Public Health Sector and the selected NGOs.

3.7.3 Data collection: children clinically diagnosed with AIDS

Data on the needs of children as identified by the children was collected by means of unstructured interview guide. An unstructured interview guide (Annexure 8) was developed for the purpose of conducting unstructured interviews with the children. Unstructured interviews are free-flowing and apply prompting questions to encourage the respondent to elaborate on the topic. The advantage is that it enhances rapport in that it indicates to the informant that the researcher is interested in understanding the informant's experience (Brink, 2006). The unstructured guide was developed to protect and be sensitive to the children who were already vulnerable due to illness. The guide was also shared with the supervisors before the final unstructured schedule was finalised. The unstructured interview guide was also discussed with experienced colleagues for input to ensure that it was sensitive and valid, that it would be understood by the children and that it would not cause them distress in any way. The unstructured interview guide was used to collect information on what the children diagnosed with AIDS identified as their needs. The opening question was 'What are your needs when you are sick' English (Annexure 8) and vernacular (Annexure 8.1).

It was important to get from the children themselves what they perceived to be their needs when they are sick. Information was obtained in a non-threatening way using an open ended unstructured interview guide, being sensitive to their health status and the fact that they were minors, English (Annexure 8) and vernacular (Annexure 8.1). Open ended unstructured interview generate rich and diverse information and it allowed the children to respond in whatever manner was suitable for them (Brink, 2006).

Informed consent was obtained from the parent/legal guardian or main carer and an assent from the child before data was collected. Explanation in simple terms was given on what the study involved. They were assured that if they were not in agreement to give informed consent to participate in the study they were free to do so and still enjoyed the full benefits of receiving standard treatment and care. The children took part when parents freely gave their consent and children their assent to participation. If additional needs were identified requiring care an opportunity for referral and linking to appropriate care provider was created, and if the child became distressed the unstructured interview would be stopped. Field notes from observation provided a record of what the researcher witnessed and heard outside the immediate context of the interview (Ritchie & Lewis, 2004).

Convenience sampling (Brink, 2006) method which is also referred to as accidental or availability sampling was applied to select the children for the study. It was based on the assumption that the participants would be in a position to unambiguously provide the

required information, was applied to select the children for the study. An open question for the children to list their needs was asked in vernacular with no promises made. The researcher is proficient in Shona vernacular. Unstructured data collection refers to responsive, flexible and interactive questioning techniques used in in-depth data collection. Collection of data continued until the point of data saturation where there was no new information coming from the children (Brink, 2006). Hence the number of children in the study was determined until data saturation was reached.

3.8 Validity, Reliability and trustworthiness

Validity is the ability of an instrument to measure the variable that it is intended to measure where as reliability refers to the consistency and dependability of a research instrument to measure a variable. Validity and reliability are important to ensure that information generated is straightforward, bears strong evidence that shows scientific rigour or robust. To ensure evidence based palliative care the instruments used were based on palliative care indicator guides (Annexure 9). In qualitative research, researchers tend to replace validity and reliability in favour of terms such as trustworthiness, dependability, credibility and transferability (Brink, 2006). In this study it is the ability of the researcher to produce trustworthy research findings. The process of ensuring validity and reliability of this research study started with the development of the study instruments. These were shared with colleagues and the supervisor and were also field tested to check instrument validity. Further, the researcher involved the key informants to review the transcript from their responses to validate and verify the researcher's interpretation and conclusion and to check the researcher's ability to collect and record information accurately.

The Palliative Care Indicator Guide (Hearn & Higginson 1999) was used to identify variables to be measured in palliative care including palliative care for children (Annexure 9). The guide was used in conjunction with the African Palliative Care Association African Palliative Outcome Scale (Annexure 10) which was validated at Kings College London School of Medicine in (2008). However, the African Palliative Care Association African POS was developed to measure the adult indicators using the adult African Palliative Care Association African POS. It therefore poses challenges as palliative care outcome scale for children is yet to be developed. In the absence of a paediatric outcome scale, the adult POS was utilized to guide the development of the instruments, as the adult POS formed the basis for palliative care for adults (Annexure 10).

The instruments that were developed were shared with supervisors and were field tested during the pilot study with experienced palliative care colleagues to ensure that the instruments were well understood and could generate information that was required to

explore whether palliative care needs of children diagnosed with AIDS were being met in Harare, Zimbabwe.

The experienced colleagues tested the instruments for suitability for use. This process was done with all the instruments that were developed for use in this study namely: the two interview guides for the Ministry of Health and Child Welfare and the selected NGOs and the interview guide for the children receiving care from the selected NGOs. The field testing was done to check instrument validity, which seeks to ascertain whether an instrument or tool accurately measures what it is supposed to measure, given the context it is applied.

Comments from the supervisors were to put some of the interview guide for the public health sector in a table form for the different levels of health care system. The process of sharing the instruments with supervisors was done to ensure content validity, which is normally used in the development of questionnaires or interview guides. Content validity is an assessment of how well the instrument represents all the components of the variable to be measured (Brink, 2006).

To ensure that the data reflected reality, validity and was trustworthy, interviews were conducted on three key informants of whom two were consultant paediatricians in the public health facility. The data from the managerial personnel of two of the selected non-governmental home based care organisations was collected in the presence of another senior staff member, to check whether the information given was correct. This however could introduce bias as some people are not free to open up in the presence of another person.

3.9 Data Analysis

The researcher collected non-numerical data in the form of words, phrases and statements from the study participants. The data included audiotapes of study participants from the Public Health and NGO sectors excluding the children. The transcripts from the Public Health and NGO sectors were verified by the participants themselves to check the accuracy of the information. There was a fair amount of data in the form of words that the researcher collected. The data was put in themes and categories to make sense of the data that had been collected. Coding was used to organise the data. Initially the data was categorised manually and verified by expert colleagues in the field of palliative care and researchers from the University of Zimbabwe. However, through sharing and asking for opinions, the researcher was assisted by another researcher to use OpenCode computer version to further analyse the data. This helped the researcher to compare the results of the themes and categories done manually and the one done using the OpenCode version. The researcher further analysed the data to come up with what is presented in this study.

Descriptive analysis which entailed describing the data in a meaningful way and using narrative strategy was applied to analyse data. The verbatim interviews formed the data set. The researcher and another researcher individually read and re-read the data sets. Common issues were identified and grouped to form themes once agreement was reached during the data analysis process (Brink, 2006).

The data collected from the children were qualitatively analysed once translated into English and the transcription back to Shona by the researcher who is totally proficient in English and Shona to ensure correct translation. Once their needs were quantified, these were group to form themes during analysis.

3.10 Summary

In Chapter three the research methodology was discussed. This study adopted purposive sampling procedure for the Ministry of Health of Health and Child Welfare and NGO key informants and convenience sampling for the children. The study sample included three informants from the Ministry of Health of Health and Child Welfare, five from the selected NGOs and twenty-two children diagnosed with AIDS. The instruments used to collect data were field tested to ensure validity and reliability. In the next chapter, the data collected from Ministry of Health, the selected NGOs and children clinically diagnosed with AIDS was presented.

CHAPTER FOUR

DATA PRESENTATION

4.1 Introduction

In this chapter the data obtained from Ministry of Health and Child Welfare, selected NGOs and children diagnosed with AIDS are presented with same level of interpretation. The presentation of the data is aligned to the purpose of the study. The overall purpose of the study is to determine what palliative care services are available for children diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The aims of the study are to: describe the palliative care services offered by the public health sector to children diagnosed with AIDS; describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS; describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided.

The services offered to AIDS diagnosed children by the public health sector are presented in Table 4.1.

Table 4.1 Summary of services offered to AIDS diagnosed children in Harare

Available care/services	Public Health Sector			NGOs
	Tertiary	Provincial	District	
Pain management on the WHO three step analgesic ladder:				
Step 1	Yes	Yes	Yes	Yes
Step 2	Yes	No	No	Yes (Limited)
Step 3	Yes	No	No	No
Manage common symptom	Yes	Yes	Yes	Yes
Manage Opportunistic Infections	Yes	Yes	Yes	Yes
Provide ART	Yes	Yes	Yes	No
Manage ART side effects	Yes	Yes	Yes	No
Provide counselling services	Yes (Limited)	Yes (Limited)	Yes (Limited)	Yes
Provide bereavement care	No	No	No	Yes
Provide carers with information to care for the sick	Yes (Limited)	Yes (Limited)	Yes (Limited)	Yes
Supply food	No	No	No	Yes (Limited)

The WHO (1998) three-step analgesic ladder pain management is available, however, levels 2 and 3 are only offered at tertiary public hospitals. Management of common symptoms, opportunistic infections and supply of ART are offered by all involved in the caring for AIDS suffering children in Harare. However, it would appear that the NGO sector is more geared to provide counselling, bereavement care and training for carers towards equipping them to care for the sick at home. The NGO sector indicated that they provide food to some extent. See Table 4.1.

4.2 Ministry of Health Officials

Three key informants from the public health sector participated in the research study.

4.2.1 Pain management

The key informants said *"Pain management is not part of the medical culture. Pain is supposed to be managed in oncology wards, if you look at the children's wards, only A4 Special children's ward, which is an oncology ward has a controlled drug cupboard and the rest of the wards do not have. They were designed not to deal with controlled medicines such as morphine"*.

The central hospitals mainly provided acute care, diagnostic and curative measures. Medicines on the WHO three step analgesic ladder were not available except for paracetamol and ibuprofen which are on the first step analgesic ladder for mild pain. Parents/legal guardians or main carers were given prescription to buy the medicines on the first step WHO analgesic ladder required for pain management. Medicines for step two and three were only available at tertiary institutions. It was reported that very little was done in the public health sector in terms of pain management and the provision of palliative care for children as a whole. Morphine was not routinely prescribed and used.

4.2.2 Symptoms management

The key informants noted that generally all symptoms were managed at all levels of the health system. Provincial hospitals and Mission hospitals had the capacity and skills to manage opportunistic infections. District hospitals were able to make referrals of children with complicated symptoms to Provincial and Mission hospitals. The doctors working at District level were few. The process of capacity development was slow at the lower levels of the health system.

The key informants in the public health sector indicated that management of common symptoms and opportunistic infections in children were done. Cotrimoxazole, a prophylaxis medication was available at all levels.

The informants said *"Erratic supplies of medicines for the management of symptoms are one of the major problems"*.

4.2.3 Provision of Highly Active Antiretroviral Therapy (HAART)

The provision of HAART was reported by the informants to be in place for few children and not enough to cater for all the children who needed to be enrolled on HAART. HAART was not decentralized and it was difficult for many children to access it. The informants reported some efforts were made to link with the communities, they also reported that referral system was weak and strengthening of the referral system was needed.

The key informants noted that up until mid 2006, the challenge was, neither suspension formulations nor paediatric dose solid formulations were available for use in children in the public health sector. Children weighing more than 15 kg were given adult formulation drugs by using various combinations of divided or crushed tablets in single drug or fixed drug combinations. Breaking tablets resulted in irregularities in dosages. On many occasions there were no pharmacists or pharmacy technicians to do the calculation and dispensing of paediatric doses, which the doctors would have prescribed. There was also an accreditation system which Ministry of Health and Child Welfare used depending on skilled personnel available at the level or site for ART provision.

Simple side effects such as skin rashes, diarrhoea and vomiting were all managed at the District level. Referrals were made depending on the grade or severity such as severe anaemia and lactic acidosis. Mission hospitals were said to be well equipped with experienced doctors, to manage side effects related to ART medicines.

"Fortunately we have not experienced many side effects related to ART medicines", one informant said.

4.2.4 Counselling services

The key informants reported some counselling was done in the public health sector; however, weak elements were noted and acknowledged by the study participants in areas such as spiritual and emotional issues. They noted the introduction of trained primary care counsellors by the Ministry of Health and Child Welfare was to relieve the work load and to

ease the burden of counselling responsibility from nurses and doctors. One central hospital in Harare had well trained nurse counsellors while the other was struggling with limited personnel to provide the counselling service. The informants indicated the primary care counsellors were doing well at their level of education, needed to be coordinated, supervised and their work monitored in order to strengthen the services provided.

The informants said there was need to improve the content of the training supported by partners of the ministry. Some challenges faced were, some primary care counsellors had more than one portfolio where they did other duties not necessarily counselling.

4.2.5 Bereavement care

The key informants said bereavement care generally was poor at all levels. They highlighted that the health care workers needed training in bereavement care. The other challenge was, there was rapid staff attrition of skilled personnel; they said training needed to be ongoing.

4.2.6 Information sharing

The key informants reported that information was shared with parents/legal guardians; they indicated that there was no systematic way of sharing information with parents/legal guardians. Sharing of information was done case by case, and not done routinely for every child. The children were rather excluded in this activity.

Said one informant:

"We do not include children in discussing their prognosis, we try not to tell children information that conveys sad news as it would upset them and also children are too young to understand what is happening around them".

The key informants confirmed efforts were made to share information on caring for the sick with the carers. According to policies, information was supposed to be shared. In the advent of ARVs information sharing was done, but it needed to be strengthened.

4.2.7 Food security

Both key informants indicated there was need to advocate for resources such as food for the needy patients. There were no resources targeted for food security in the public health sector.

"Children who are admitted with acute malnutrition are put on high energy foods and formula; at least that is what we can afford", said one informant.

In some instances children were referred to organisations that provided food, however the informants noted the organisations that provided food were not many, and the donors that supported the provision of food in Zimbabwe were few. It was reported the Ministry of Health and Child Welfare was working with partners and stakeholders that sourced and assisted with food for the patients both adults and children such as Zimbabwe Aids Network (ZAN) and World Food Programme. The Ministry of Health was said to be making efforts to link care, treatment and food. This included TB and other debilitating conditions.

4.2.8 Challenges faced in implementing palliative care for children in Hospital

The key informants said the central institutions basically looked after poor people who were not able to pay for the services offered. The institutions also needed to recover some money for sustainability. Children <5 years were offered free treatment. The mothers stayed with their children throughout the day till late and there was no sleeping facility for the mothers who may have wanted to stay with their children overnight; they ended up looking for food to buy outside the hospital, which was very expensive for them to sustain.

They said "Children would like to be with their mothers and we know that it is very therapeutic. The paediatricians as well as the nurses would like to offer holistic care, which include counselling, pain management and rehabilitation, but we have constraints in resources".

The informants recommended palliative care and pain management be addressed during counselling training. The counsellors would then help to identify the children for palliative care to enable the continuum of care for the children. It would maximize the work of the counsellors who were already in place. Development of a curriculum for palliative care to be incorporated into the training of counsellors would equip the counsellors with skills needed to promote palliative care for children and adults. The counsellors would constantly remind the doctors that it was an important part of their culture to provide pain management. In general the ministry had identified three major challenges that were faced by public health sector, namely:

- Access to vital palliative care drugs;
- Access to other commodities such as gloves, disinfectants and protective clothing for the primary and secondary caregivers, and
- Human resources.

The informant said *"Due to financial constraints and competition for the limited available resources palliative care medicines are taken as second priority"*.

It was reported by the informants that within the hospital there was not enough advocacy taking place for the needs of chronically ill children. The informants indicated there was need for training to make health professionals aware of palliative care and the needs of children with ill health. The hospital mainly provided for acute care and there was no separate ward for children with chronic illness. Staff shortage of both doctors and nurses compounded to the problem. Both doctors and nurses were not trained in palliative care. There was need to make morphine widely available and used, it was not widely used due to lack of training in its uses.

4.2.9 Palliative care for children discharged from hospital

The key informants said there was generally not enough interaction with the community. They cited lack of adequate information on what services were available in the community.

One of the key informant said *"We do not want to let go of the children because we do not trust the care that will be provided in the community by other care providers. We are not sure of what help will be provided for the children once discharged from the hospital."*

The key informants were aware of the financial constraints which families faced in terms of transport for subsequent reviews.

Key informants indicated the ministry had a Discharge Plan policy document that was put in place for cervical cancer patients, the same policy applied to HIV and AIDS and other chronic illnesses. It allowed referrals and links with the community support groups, churches and families where available. Families could then collect commodities and supplies for the patient at home in order to maintain the continuum of care for the patient and family. At the community level there were village health workers whose job was to assess their communities as part of the District Health team. Economic challenges were said to be undermining this effort.

4.2.10 Challenges faced in implementing palliative care programmes for children

The informants indicated there was no capacity to run the opportunistic infection clinic for AIDS diagnosed children who come back for reviews. In the past the clinic was managed by a nurse, the situation had since changed with doctors running the clinic with nurse-aids who were not qualified to identify the issues that concern children and their families. The

informants cited lack of information on how the community nurses managed the children in the community, doctors were inclined to hold on to the children and not let go because they were not sure of what would happen to the children after their release from the hospitals.

The informants noted the need for more home based care training to provide quality care once the child has been discharged from the hospital there. The informants highlighted that parents/legal guardians or main carers of children lacked knowledge and skills on how to care in end of life as it is often difficult and stressful to provide end of life care. Caregivers tended to abandon patients when they were at the end of life and would dump the children in hospitals. There was very little link between hospital and community, though both people on either side were required for the continuum of care for children to be effective.

“People have to develop a passion for palliative care for children rather than being expected as just an ordinary job. Children diagnosed with AIDS face many problems with disease, symptoms, side effects and treatment of opportunistic infections. Adolescents also face challenges that are unique, hence health care workers require training in palliative care which is lacking and this leads to care being compromised”, said one key informant.

4.2.11 Overall Comments from the key informants

The key informants expressed concern at the lack of provision of palliative care for children. Large numbers of children were in need of palliative care. There was a shortage of medicines, and although some medicines were manufactured in Zimbabwe they still required foreign currency to buy raw materials. Morphine availability for pain management and supplies, in the hospitals were at times very erratic and unpredictable. The issues of discharge planning was not being practiced, children were discharged without any follow up.

Traditionally palliative care and pain management was known to be for the dying. In hospitals those who needed pain management were cancer patients with chronic illness. Oncology was associated with pain relief and pain management was done in paediatric oncology wards only. Even cupboards for storage of controlled drugs such as morphine were not in any children's wards except the oncology ward. There was need for a paradigm shift where doctors are more aware of children's pain and in management of it. Many doctors had not caught up with pain management in HIV and AIDS. Tradition of home based care was that everything was lumped up in home based care without capacity building to enable quality care and to critically differentiate between palliative care and home based care.

The key informants with the public health sector identified major challenges that include;

Food security: Patients both adults and children could not access appropriate diet. There is need to document and make follow up on dietary requirements of sick children.

“There is lack of commodities such as gloves and protective clothing. If provincial hospitals do not have these commodities it will be a dream for communities to have. Communities are simply forgotten” said one informant.

4.2.12 Finances and transport

The informants said patients and families paid exorbitant transport costs to attend to hospital reviews and check up at the nearest clinics.

“Even physically short distance can be too much for a sick person to walk. In most cases there is no means of transport in the rural areas and use of wheel barrows is not always available for most families. Unfortunately these challenges result in child labour and abuse” said an informant.

4.2.13 Suggestions from the key informants

The informants suggested that:

- Palliative care is incorporated into training of health care workers at every level, for example, doctors, nurses, physiotherapist, rehabilitation staff, counsellors and social workers.
- Much advocacy was needed, relevant medicines were not ordered as doctors and nurses did not know how to use them, pain was associated or regarded as an oncology ward prerogative.

The study participants reported there was limited palliative care provided for AIDS diagnosed children in the public health sector, for example in cases of acute malnutrition, children were admitted for high energy foods and formula. Further, at one of the Central hospitals free medical treatment was provided to children <5 years old. Financial constraints and staff shortages limited the care nurses and doctors would have liked to provide, versus the care they could afford to render. It was also reported that staff members were aware of the need for pain management and that nurses and doctors working in the public health facilities were not palliative trained.

4.3 Selected NGOs

Data collected from the three selected NGOs on their staff complement is presented in Table 4.2.

Table 4.2 NGO Staff complement

Selected NGOs	Health care worker	M	F	P C trained	Full time	Part time	Vol	In patient	HBC
NGO 1	Nurse	0	2	Yes	2	0	0	N/A	2
	S/worker	1	0	Yes	1	0	0	N/A	1
	Doctor	0	0	0	0	0	0	N/A	0
	Caregiver	40	420	176	0	0	460	N/A	460
Total		41	420	176	0	0	460	N/A	463
NGO 2	Nurse	0	3	0	0	3 (complement of Island Hospice)	0	N/A	0
	S/worker	1	0	0	0	1 (complement of Island Hospice)	0	N/A	0
	Doctor	1	0	0	0	1 (complement of Island Hospice)	0	N/A	0
	Caregiver	3	69	30	0	0	72	N/A	72
Total		5	72	30	0	5	72	N/A	72
NGO 3	Nurse	4	12	1	13	2	0	9	7
	S/worker	0	0	0	0	0	0	0	0
	Doctor	1	1	0	2	0	0	2	0
	Caregiver	5	152	30	0	0	157	7	150
Total		10	165	31	15	2	157	18	157

- P C = Palliative Care
- Vol = Voluntary
- HBC = Home Based Care

One NGO as reflected in Table 4.2 had a nurse and social worker who had received palliative care training, while the other NGO had no health professionals on the staff complement. The third NGO, a faith based organisation had nurses and medical doctors on full time basis. The NGO that had no health professionals on the staff complement relied on a well established palliative care organisation that assisted by holding opportunistic infection clinic once a month to help the organisation with difficult and complicated conditions of patients and families that required palliative care. The NGO sector had a strong complement of community caregivers, some of whom had received training in palliative care for children offered by Hospice and Palliative Care Association of Zimbabwe as part of implementing the programme of support under the National Activity Plan for Orphans and Vulnerable Children.

The AIDS diagnosed children who were cared for by the three selected NGOs are presented in Table 4.3.

Table 4.3 Total number of AIDS diagnosed children receiving care from the NGO sector

Selected NGOs	Age in years				HBC	Institution Admission	Total Number of children
	0 - 3	4 - 8	9 - 13	14 - 18			
NGO 1	74	93	207	86	460	0	460
NGO 2	3	21	33	17	74	0	74
NGO 3	45	127	125	89	362	24	386
Total	122	241	365	192	896	24	920

In total 920 children aged from 0-18 years old were cared for by the selected NGOs. The majority of children are between the ages of 4-13 years old. The three organisations represent a small area of Harare in Zimbabwe, with so many children who are sick with AIDS.

4.3.1 Selected NGOs' understanding of palliative care for children

The key informants from the selected NGOs highlighted the following issues as being crucial for palliative care for children; provision of ART , social and emotional support, bereavement services for children and family, treatment of opportunistic infections, play and games for children, providing education including health and provision of social component such as feeding programme, school fees and accommodation. One key informant from one organisation mentioned pain management and family support as a crucial component of palliative care.

4.3.2 Palliative care components provided by the selected NGOs

The informants noted the following were palliative care components which were provided to children they were caring for; social, physical, spiritual, emotional and bereavement care. Social components included feeding programme, school fees and accommodation for the children. On physical needs they highlighted medicines for pain and symptom management. Children were encouraged to attend church and/or cultural rituals depending on their cultural and spiritual beliefs. Counselling on issues of illness and bereavement were provided to children and their families for addressing emotional components.

4.3.3 Pain management

The study participants said most children had their pain managed on the first and second steps of the WHO analgesic ladder using medicines such as paracetamol, codeine phosphate, indomethacin, ibuprofen, diclofenac and stopayne syrup. However medicines for moderate pain were limited and severe pain were not available due to unavailability in Zimbabwe.

4.3.4 Symptom management

The study participants highlighted common symptoms such as diarrhoea, fever, cough; oral sores and skin rashes were managed well by all the three selected organisations. Two of the organisations had a wide range of antibiotics normally used for symptom management.

4.3.5 Provision of ART

Provision of ART was mainly through a referral system from hospitals, clinics and other care organisations for them to follow up the children at home. Children who were referred while on ART were offered support through home visits. All the organisations initiated counselling, testing and enrolment of children on ART by referring them to institutions and opportunistic infection clinics where they could access the services. Provision of adherence to treatment counselling and education was given and continuous monitoring and support was done through home visits. All the organisations highlighted the importance of understanding ART and giving of information and counselling on HIV and AIDS issues.

4.3.6 Counselling services

Counselling services were provided for families by the selected NGOs. The key informants noted that it was difficult to talk to children about death and dying as it was culturally a taboo for everyone and especially with children. Communicating with children was said to be difficult as the carers had limited communication skills to provide effective communication with the children. They opted to communicate through parents/guardians when condition of the child deteriorated. For the children who were mobile support was offered through psychosocial support camps and support groups. Only one organisation reported offering emotional and spiritual counselling sessions, and discussions were done on death and dying issues. Psychosocial support and family support relating to losses were offered.

4.3.7 Bereavement care

Bereavement support was provided for the children who were bereaved. The key informants highlighted that it was difficult for both health professionals and caregivers to discuss death and dying issues with the children as it was considered a taboo.

4.3.8 Family Support

The informants highlighted that families were supported through various support systems put in place by the organisations. The two organisations that were well established provided transport for reviews at hospitals. The families and children received information on basic home based care skills on how to look after a sick child or relative at home. Free medical treatment and free consultations were offered by two of the organisations. Children were engaged in support groups where they shared information and experiences. The families were assisted with home based care kits which contains gloves, soap, paracetamol and wound dressings when available for use in the home when caring for the children. The selected NGOs worked with other care providers such as Social Welfare and other care organisations and refer children for further assistance as and when required.

4.3.9 Food security

The organisation that was in the peri-urban area of Harare realized the magnitude of the problem of inadequate food; they mobilized vegetables from community gardens which they distributed to children in need of food. One informant reported that the community was involved in the contribution of basic food items for the welfare of children in their area. The two NGOs had a supplementary feeding scheme and monthly provision of food packs. Many children were reported as hardly having one meal a day. Due to the magnitude of the problem, it had the provision of agriculture inputs, training families on low input gardens and information was shared and given on nutrition and types of food available in that particular community. The following was a summary of support given to families: basic home based care skills, referral to Social Welfare, Basic Education Assistance Module (BEAM), free medication and consultation, transport for reviews, counselling on illness issues and information on care.

4.3.10 Information sharing

The key informants noted organisations shared information with children, parents/legal guardians and other stakeholders using parental education, workshops, drama and sports, monthly meeting with caregivers and staff effectively. Education on prevention was given to

both children and families. Sharing sad information with the children such as poor prognosis was highlighted as very challenging and requiring more skills.

4.3.11 Play and education

The informants reported play and education were well provided for. The informants said children were allowed to play during support groups games, psychosocial support camps and had designated areas where the children could play. All the organisations had recreation kits for the children to utilize during playing time. Further, study participants highlighted that health education and provision of school fees and educational materials were done by two of the organisations. Where the organisation had no resources the children were referred for special assistance from Ministry of Education.

4.3.12 Integration of activities into home based care

The informants indicated that all their activities were centred on home based care as children were identified through home base care activities. Efforts were made to deliberately integrate programme activities into home based care in order to provide a comprehensive care package that included follow up of children into the communities.

4.3.13 Access to NGO services

The key informants reported that the organisations worked closely with relevant authorities in their area of operation. Children accessed services through the following: through referrals from hospitals, clinics, local leaders, police, identified by community based caregivers, through stakeholders networking meetings and from Social Services. Individuals who knew about the NGOs also make referrals to these organisations.

4.3.14 Challenges faced by NGOs in providing palliative care for children

The informants indicated the following challenges faced by the organisations:

- Lack of pain management medicines on the second and third step WHO analgesic ladder such as codeine and morphine;
- Limited resources available such as care kits, medicines, food, shelter and blankets;
- Children expected more than what the organisations could offer such as school fees, shelter, blankets, clothes , respite for both the child and the primary carers and food for the children;
- Limited human resources as there were few trained caregivers available as compared to comprehensive coverage., and

- Lacked training in Palliative Care for both adults and children.

The other challenges faced by individual organisations included the issue of volunteers' incentives which was not in place as the organisations could not afford to provide monetary incentives. One of the organisations relied on other organisations to assist as it had no health professional on its staff complement. The faith based organisation that had an in-unit for both adults and children cited the problem of families who were not supportive; who at times would dump children at the centre when they were very sick and never looked back. The informants stated it was very difficult and challenging dealing and communicating with children in issues of illness, death and dying on a large scale.

4.3.15 General Observation

Study participants from the three organisations reported that they were facing challenges in acquiring pain management medicines according to WHO analgesic pain ladder, at the time of collecting data. Two of the organisations had medicines on the first step analgesic ladder, while one had nothing in stock for pain management. The organisation faced many challenges in terms of supplies and resources, and often appealed for assistance from other organisations. It was stated that patients who were referred while on strong analgesic such as morphine, continued to be monitored and provided support at their homes, thereby strengthening the continuum of care. All the three selected NGOs stated they worked very closely with other care providers. Many of the children visited were orphans being looked after by relatives.

4.4 Children diagnosed with AIDS

4.4.1 Demographic characteristics of AIDS diagnosed children participants.

Table 4.4 Age Range of AIDS diagnosed Children

Age Range	Frequency N (%)
4 – 7 years	5 (22.7)
8 – 10 years	7 (32)
11 – 13 years	2 (9)
14 – 16 years	3 (13.6)
17 – 18 years	5 (22.7)
Total	22 (100)

A total of 22 children (12 male and 10 female) whose parents/legal guardians or main carer consented and also either assented or gave consent participated in the study. Children's ages ranged from 4 - 18 years old with more than half (54%) aged 4-10 years.

4.4.2 Children's needs as they perceive them

The children highlighted their needs as tabled in Table 4.5. Needs with highest frequencies were food, play, clothes, education and treatment.

Table 4.5 AIDS diagnosed Children's needs versus what is offered by the public health sector and NGOs (n=22)

Needs indicated	Frequency n (%)	Public health sector	NGOs
Food	19 (86.4)	No	Yes (Limited)
Play, Toys	16 (72.7)	No	Yes
Clothes, Blankets	11 (50.0)	No	No
Going to school, Education	9 (40.9)	No	Yes (limited)
Medicines, to get better/to get well	7 (31.8)	Yes	Yes
School uniform	3 (13.6)	No	No
Accommodation	2 (9.1)	No	No
Listening to radio	1 (4.5)	No	No
Sharing information with other children	1 (4.5)	No	Yes
Mosquito pellets	1 (4.5)	No	No

Table 4.5 presents the needs of children as perceived by them versus what is offered by the public health and the NGOs sectors. The public health sector provides only one (medicines) out of all the needs specified by the children. While the NGO sector provides four of the first five prioritized needs, it is noted that two out of the four needs are provided in limited amounts.

4.4.3 Food

The children who expressed the need for food were (19/22) 86.4% of the children who participated in the study. See Table 4.5.

A child said *"I need food, I am always hungry. Gogo(grandmother) does not have enough food for us"*.

Another child who was almost in tears reported the family had not had any meal for a day and when asked to elaborate, it was a second day without food and was not sure where the next meal would come from. The children expressed that they needed good food that was prepared well, such as having cooking oil in the relish. Some children who mentioned food had actually no food in the home and were not sure of the next available meal.

"We will be happy if you can find us some food, I am staying with my mother's sister and she is too sick to fend for us, my two brothers and her three children", said one child.

4.4.4 Play

The children highlighted play as their second need. This constituted (16/22) 72.7% of the children who participated in the study. They mentioned the desire to have plenty of toys and the need to play with others. See Table 4.5.

One child said, *"All my friends are always at school and I am alone all the time. My friend was told by his mother not to play with me because he can also get sick like me"*.

Boys wanted to play soccer.

4.4.5 Clothes

The children indicated they needed clothes. A total of eleven children 11/22(50%) expressed the need to have clothes and blankets. Some children had only one blanket to share among the entire number of children both boys and girls in a household, at times that included boys who were much older. See Table 4.5.

4.4.6 Education

The children expressed the need to attend school like other children. This constituted (9/22)40.9% of the children who participated in the study. The children highlighted the need to have full school uniforms to identify with other children in their respective classes. See Table 4.5.

4.4.7 Medicines

A total of seven children 7/22(32%) wanted to have enough medicines so they could get better. Some children said medicines are not always available at the clinic and the organisation that was providing care did not always have either. See Table 4.5.

"We do not have the money to buy medicines. At times the pain stops when I go to sleep", said one child.

The children wanted to get better so that they could attend school and be able to play with the other children.

The children also highlighted the following as part of what they perceive as necessary needs when they are sick; accommodation, listening to radio, sharing information with other children and mosquito pellets.

4.5 Summary

The data collected from the public health sector, selected NGOs and the children who participated in the study was presented in this chapter. While the public health sector is the biggest provider of health care services, it is facing major challenges in the provision of palliative care for children due to lack of access to ART, pain and symptom and palliative care trained personnel. The selected NGOs have a strong counselling component in bereavement care and counselling services for emotional, spiritual and social issues. The NGOs also meets more of the perceived needs of children diagnosed with AIDS in Harare than the public health sector does. Discussions on findings will be presented in detail in chapter five.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The aims of this descriptive study are to: describe the palliative care services offered by the public health sector to children diagnosed with AIDS; describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS; describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided. Three health officials from the Ministry of Health and Child Welfare, five senior personnel from three NGOs and 22 children diagnosed with AIDS were interviewed. The children comprised of 12 males and 19 females. Study findings indicate that the needs of children diagnosed with AIDS are similar to the developmental needs of any child namely food (86%), play, toys (73%), clothes, blankets (50%), going to school, education (41%) and medicines to get better (32%). However the public health sector and the NGOs were unable to provide palliative care that was meeting the identified needs of children. The public health sector provided medication needs, while NGOs provided limited food and schooling, play/toys and medicines. Both sectors did not provide clothes and blankets. The rough economic environment in Zimbabwe with attendant poverty, nutritional deficits and poorly developed health and education services puts the child diagnosed with AIDS at risk developmentally as reported by Marston (2006).

5.2 Services offered by Public Sector and NGOs

5.2.1 Pain management

Only medicines for step one WHO analgesic ladder such as paracetamol and ibuprofen were available in the public and NGO sectors. Medicines for step two and three were available only at tertiary level Table 4.1. Morphine is not routinely prescribed and used. Pain is thus not alleviated as children cannot always articulate pain and often do not complain at times as reported by Hospice Africa Uganda (2006). In general, the results of this study show that the NGOs were providing some 50% components of palliative care, to children clinically diagnosed with AIDS. The NGOs in Harare provided pain management as palliative care service only up to the first and second step on the WHO analgesic ladder that seeks to address mild and moderate pain. However medicines for step two analgesic ladder were very limited. They lacked medicines for severe pain management; hence children with moderate to severe pain were not well managed. One NGO reported that they were not allowed to deal with essential medicines that control pain due to the absence of qualified personnel. Caregivers alone could not provide critical palliative care services such as administering medicines like morphine and ART. Based on the number of children the NGOs were looking

after during data collection, it would appear that there was very high demand for palliative care services for children diagnosed with AIDS. See Table 4.3.

5.2.2 Symptom management in HIV and AIDS

Lack of access for ART and erratic supplies for treating opportunistic infections affect symptom management and quality of care. In the absence of treatment with ART as in the case of NGOs and lack of paediatric formulations in public sector, the child is prone to opportunistic infections which are painful, debilitating and affect the quality of life as reported by Harding et al. (2007). Yet according to Doyle and Woodruff (2008) provision of palliative care was a response to suffering and to identify patients' needs so that the pain can be alleviated.

While the public health sector had access to medicines for all the WHO analgesic step ladder, medicines for moderate to severe pain were not prescribed by the doctors due lack of training in pain management and palliative care in general. Although some pain management was provided by the NGOs, they fell short of providing the recommended WHO three-step analgesic ladder. None of the organisations included in this study, were authorized to keep controlled drugs such as morphine as it required special registration of the organisations and trained health professional to prescribe them. Patients referred to the organisations while on morphine were followed up and monitored through home visits by the health care workers and volunteers of the NGOs, but did not have stocks to use when the patients had run out of analgesics.

5.2.3 Counselling Services

Limited counselling services in the public health sector in areas such as spiritual and emotional issues due to personnel with limited training in counselling and some personnel doing other duties besides counselling. The NGO sector provided counselling services for families but informants found it difficult to talk to children about death and dying as it is culturally taboo for everyone, more so with children. Only one organisation offered emotional and spiritual counselling services and discussions on death and dying issues. This finding appears to support what UNICEF (2006) reported that little attention is given to psychosocial needs of children. Psychosocial support would enhance coping with fears and emotions, providing holistic care.

5.2.4 Bereavement Care

It was reported that there was lack of bereavement at all levels in the public health sector due to lack of training in bereavement care and rapid staff attrition of skilled personnel. However, the three selected NGOs provided bereavement support for the children where indicated to give them an opportunity to express their feelings as reported by Marston (2006). The public health sector is thus addressing physical needs only, a finding in line with UNICEF (2004) study which noted that only 1% of assistance to orphans and vulnerable children (OVC) was in emotional and psychological care. Similarly, less than 5% to both OVC and chronically ill was emotional and psychological support (Zimbabwe MOH&CW, 2005).

5.2.5 Information Sharing

Information sharing of the public health sector with patients/legal guardians was not systematic, not given routinely and excluded children as they were reported to be too young to understand what was happening. While the selected NGOs used formal channels of communication such as workshops, drama and sports and meetings with caregivers, participants reported that they require more skills on sharing information where there was a poor prognosis. They opted to communicate through parents/legal guardians or main carer when the condition of the child deteriorated. Yet Marston (2006) indicated that palliative care for children must be delivered in line with developmental stages which relate to how children respond to situations at different times of their growing, how they communicate and their understanding of situations such as death. Moreover, the African Charter on the Rights and Welfare of the Child (1990) advocates those children should be prepared for impending death by discussing the children's illness with them to overcome their fears and worries.

5.2.6 Provision of Food Security

There were no resources for food provision in the public health sector. In some instances children were referred to organisations that provided food, which at the time of this study were few. Food provision was limited in the selected NGOs as many children were reported as having one meal a day. One NGO distributed vegetables from community gardens to children in need of food. The other two NGOs had a supplementary feeding scheme and provided food packs monthly. Lack of adequate nutrition is detrimental to all children. Food is even more important to a child with AIDS as the immune system needs a balanced diet to work well (Zimbabwe MOH &CW, 2006a).

5.3 Children's Needs

The needs of the children correspond very well with Maslow's (1970) hierarchy of needs in many ways. Although the children's needs formed the basic needs as highlighted by Maslow, the public health sector and the NGOs were unable to provide palliative care that was meeting the identified needs of children. Children identified food (86%), play (73%) clothes (59%), education (41%) and medicines (32%) as their five uppermost needs. Sadly, the public sector only provided medicines out of the five identified needs of children, while the selected NGOs provided limited food supplies, limited education and adequate play/toys and medicines. Both sectors did not provide clothes or blankets.

5.3.1 Food

Food remained the greatest need of the children diagnosed with AIDS, yet it was hardly provided by the public sector and was provided in limited amounts by the selected NGOs. The parents/legal guardians and caregivers were left with the burden of sourcing for food in a very harsh economic environment.

5.3.2 Play

While the selected NGOs reported that play was well provided for through support group games, camps and provision of recreation kits, the children highlighted play as their second need. They mentioned the desire to have plenty of toys and the need to play with others. This need should be addressed to provide developmental stimulation and minimise isolation.

5.3.3 Clothes and Blankets

Clothes and blankets were identified by the children diagnosed with AIDS as their third uppermost need. The NGOs reported that clothes and blankets were among the challenges they faced as the children needed more than what organisations could offer due to limited resources.

5.3.4 Education

Children expressed the need to attend school like other children as their fourth priority need. The NGOs reported limited provision of education and school fees. Where the NGOs had no resources, the children were referred for special assistance from the Ministry of Education.

5.3.5 Medicines

The study also revealed the critical shortage of medicines greatly militates against the provision of palliative care. In order for other palliative care services such as spiritual and emotional counselling and support for the family to be successful, pain management for the relief of physical pain had to be in place at all levels of health care (WHO, 2007a). This was achieved in the public health sector through availability of WHO three step analgesic ladder which in principle was included in the Essential Drug List of Zimbabwe though the medicines were practically not available.

While Morphine was identified as an Essential Drug, on the Essential Drug List of Zimbabwe (2006), it was not commonly prescribed by the doctors at tertiary level, according to study informants (Section 4.2.1). What the informants cited was lack of training of doctors and nurses to be able to assess pain and manage it effectively. Palliative care medicines in the Essential Drug List of Zimbabwe (2006) were not prescribed and often not available. The informants reported that the unavailability of medicines at the public health facility made doctors to provide parents/guardians or main carer with prescription to buy from private pharmacies, which was very expensive for most families.

5.4 Challenges in providing palliative care for children

This study's findings may be a reflection of AIDS diagnosed children's needs being met in Sub-Saharan Africa. It is startling to realize that such basic palliative care services for children were either not available or limited in its availability. Some of the challenges to providing palliative care to the children of Africa are the impact of poverty that ravages most parts of the African continent and limited palliative care trained health care workers. There is need to have pain and symptom control grafted onto supportive programmes in Africa.

The Palliative Care Indicator guide (Hearn & Higginson 1999) and the African Palliative Care Association African POS (2006) are both highlighting the need to have comprehensive palliative care provision to adults and children who require palliative care. The aim of the study was to establish whether palliative care needs of children diagnosed with AIDS were being met in line with the Palliative Care Indicator guide and the African Palliative Care Association African POS. The study has shown that according to the Palliative Care Indicator guide and the African Palliative Care Association African POS, palliative care for children is compromised.

Harding, Powell, Downing, Connor, Mwangi-Powell, Defilippi, Cameron, Garanganga, Kikule and Alexander (2008;36:306) highlighted that "palliative care measures developed and validated in Africa is a fundamental challenge to establishing a rigorous evidence base for

the continent". Harding *et al.*, (2008) further highlighted that 90% of the 2.3 million children worldwide living with HIV are in Africa; yet validated paediatric measures are insufficient. It only shows that generally children who require palliative care in Africa are neglected, and this is so in Zimbabwe as shown by the research study.

5.5 Needs of AIDS diagnosed children versus the services offered by the Public and NGO sectors

The children highlighted the following as their needs, food (86%), play, toys (73%), clothes, blankets (50%), going to school, education (41%) and medicines to get better (32%). Out of all the needs specified by the children, the public health sector managed to provide only one (medicines). While the NGO sector provided food, play, education, medicines and sharing information, it is however noted that food and education are provided in limited amounts. The needs which were highlighted by the children are basic human needs as indicated in Maslow (1970) hierarchy of needs. The basic needs in Maslow's hierarchy of needs include food, water, sleep, health, shelter among others. Furthermore, Erikson (1963) emphasizes that a person needs adequate caregiver relationship, stability, guidance, safe environment, encouragement, acceptance and continuity right from infancy.

5.6 Concluding remarks

In conclusion, meeting the palliative care needs of AIDS diagnosed children was greatly compromised in the area of food, pain and symptom management. The AIDS diagnosed children's needs with highest frequencies were food, play, clothes, education and treatment, yet only 25% of these needs were met by the Public Health Sector and the selected NGOs. This posed a great challenge indeed as there was a huge gap in palliative care knowledge and skill to provide quality care that is holistic. A comparison of what the AIDS diagnosed children perceived as their needs versus what was provided by the public health and NGOs sectors in Harare indicate that the palliative care service delivery in Harare is partly meeting one of their needs. WHO (2007a) recommended that palliative care be mainstreamed in the public health sector as a public health strategy to facilitate access for everyone who needs palliative care. Zimbabwe is yet to implement palliative care as a public health strategy.

Further, only one (medicines) of the needs of the AIDS diagnosed children in Harare, Zimbabwe is met by the Public Health sector whereas five (food, schooling, play, medicines and sharing information with others) of their needs are met by the NGO sector. Financial and resource constraints and the complex environment contributed to the difficulties faced by both the public health sector and the NGO sector as they aim to provide the needs of AIDS diagnosed children.

The needs of children in palliative care in Zimbabwe are not met in accordance to their expectations by any one of the current service providers. However, their needs are very basic and can largely be offered by community members.

5.7 Limitations of the study

The research study was limited to Harare, Zimbabwe. However, a general picture of palliative care services provided by the public health sector was highlighted by Ministry of Health key informants. Due to the fact that this study was carried out in Harare with three selected organisations and children receiving care from the selected organisations, it cannot be generalised to the context of the whole of Zimbabwe and the care provided by NGOs. The sample size would only suite making of inferences as compared conclusive generalisations. Further studies in other parts of the country can strengthen the research finding of this study and further develop strategies to improving palliative care for children affected by HIV and AIDS.

The researcher is employed full time. During the time the study was conducted Zimbabwe was facing economic challenges that resulted in regular power cuts almost on an everyday basis which made it difficult to do any work in terms of typing the research document, photocopying and use of library and internet. It also affected telecommunication as telephones and network was also affected making it difficult to make appointments with study participants.

CHAPTER SIX

CONCLUDING REMARKS AND RECOMMENDATIONS

6.1 Introduction

In chapter five the research findings were discussed. The overall purpose of the study is to determine what palliative care services are available for children (0-18 years) diagnosed with AIDS in Harare, Zimbabwe and whether the services provided meet the palliative care needs of the children. The aims of the study are to: describe the palliative care services offered by the public health sector to children diagnosed with AIDS; describe the extent of palliative care services offered by NGOs sector to children diagnosed with AIDS; describe what children diagnosed with AIDS perceive as their care needs; and to compare the needs of the children with the services provided. The researcher was guided by the palliative care indicator guide, (Hearn & Higginson 1999) and the African Palliative Care Association African Palliative Outcome Scale (2006) to develop the data collection instrument to explore whether palliative care needs of children diagnosed with AIDS were being met in Harare, Zimbabwe.

6.2 Concluding remarks

The literature indicated that by the end of 2007 an estimated 22 million people in sub-Saharan Africa were living with HIV/AIDS. Of these, 1.8 million (33%) were children under the age of 15 years. It further highlighted the state of HIV/AIDS problem in Zimbabwe; that 120 000 children below age of 15 years are living with HIV/AIDS and an estimated 1 000 000 children below 18 years were orphans due to HIV and AIDS (Section 1.7). While palliative care supports treatment adherence ART, it is also a crucial component of health care since there is a high prevalence of pain and symptoms throughout the HIV disease trajectory which needs to be managed and controlled (Section 2.3.2). Yet the literature (Chapter 2) revealed a number of challenges to providing palliative care that include: few programmes providing palliative care for children in Africa, poor understanding of paediatric palliative care and few training courses available in Africa.

6.3 Recommendations

Based on the study findings, the following recommendations are made:

- The public health sector should work in collaboration with NGOs in the community to ensure that food is available to the children diagnosed with AIDS in order to ensure normal growth and development and strengthen the immune system.
- Community members should assist in the provision of play to children with AIDS. Grandmothers should be equipped with basic information so that they can be a

resource for children to play with so that play is provided in the public sector in order to stimulate the children. This can be provided by available members of the family /community who in turn would free up the overburdened health staff professionals to offer the medical care they require.

- Clothes and blankets should be provided by both the public health sector and NGOs as a basic need to keep the children warm.
- Education is a social developmental need which must be provided and met if children are to develop their full potential.
- Social workers, doctors and nurses training in palliative care is essential in order to build palliative care knowledge among all different members of the multidisciplinary team dealing with children diagnosed with AIDS. The training should include pain and symptom management for nurses and doctors in order to provide effective pain management and improve quality of life for the children. Core palliative care topics can be incorporated into the curriculum of health care workers.
- Provision of paediatric formulations of ART and adequate for all sectors. Supplies of cotrimoxazole to be consistent to treat opportunistic infections. Second and third step medicines such as codeine and morphine to be supplied to NGOs who have appropriately trained health professionals on their staff complement.
- Administrators should make resources such as human resources, gloves, disinfectants and protective clothing for caregivers, available.
- Counselling be improved in the Public Health Sector for holistic care (holistic includes spiritual, social, physical and emotional issues).
- Bereavement care be implemented in Public Health Sector and all NGO sectors.
- The Ministry of Health and Child Welfare should hold through the public health sector, awareness campaigns to conscientise stakeholders, well wishers and the general public to be involved in the provision of palliative care especially for children.
- Palliative care be integrated into home based care in order to improve quality care for the children clinically diagnosed with AIDS in Zimbabwe as a whole, as many children are cared for through NGOs in the community.

- APCA POS for children should be developed and validated as a priority for palliative care for children, to assist and guide health care providers in the assessment of the quality of palliative care that is provided for children diagnosed with AIDS in Africa.

6.4 Concluding remarks

The Public Health Sector aims to provide medicines for AIDS diagnosed children, where as their needs include very basic issues such as having food, being loved, attending school and play. The services do not meet the needs of the children. The communities can be encouraged to provide these basic needs so that health care professionals can focus on issues such as pain control and other medications. The NGOs and community sectors meet the non-medical needs of the AIDS diagnosed children in palliative care and in so doing complement the Public Health Sector.

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**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

10th September 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Director
AIDS and TB Programme
Ministry of Health and Child Welfare
P O Box CY 1122
Causeway
Harare

Dear Dr. O Mugurungi

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) and involved in Ministry of Health activities. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology (CPUT), South Africa. This requires of me to submit a well-documented research study on "**PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE**". This research study will be carried out at three selected palliative care organizations within Harare.

I would like to seek your permission to conduct an interview with yourself in order to establish the Public Health Sector services available for children clinically diagnosed with AIDS in Zimbabwe.

Data collection will be done through a structured interview with senior management of the organizations. However data collection for this study from the children will be done through an open question and observation in the presence of the manager and parent/guardian to ensure that the rights of the children who are already vulnerable due to illness will be preserved. The data from the children will be collected by Eunice Garanganga; RN, BSc Counselling, Diploma in Palliative Care. Informed consent will be obtained from the participants who are voluntarily willing to participate in the study without any coercion. Assent will be obtained from the children. Informed consent form is attached. The study will be carried out after ethical approval for the study by the CPUT Health Sciences Research Ethics Committee and the Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated if you could allow me the opportunity to carry out this research for my career advancement and future contribution to the enhancement of national health services. I am conducting the research as a requirement towards obtaining masters in nursing qualification. This is intended specially to inform the Public Health Sector the importance of palliative care needs of children clinically diagnosed with AIDS.

Thank you

Yours sincerely

Mrs. Eunice Garanganga
Contact details: Tel 263 4 2900369 Bus
Mobile 263 11 218 292

**Study title: TO EXPLORE TO WHAT EXTENT THE PALLIATIVE CARE
NEEDS OF CHILDREN CLINICALLY DIAGNOSED WITH AIDS ARE BEING
MET IN HARARE, ZIMBABWE**

17 August 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Director
AIDS and TB Programme
Ministry of Health and Child Welfare
P O Box CY 1122
Causeway
Harare

Dear Dr. O Mugurungi

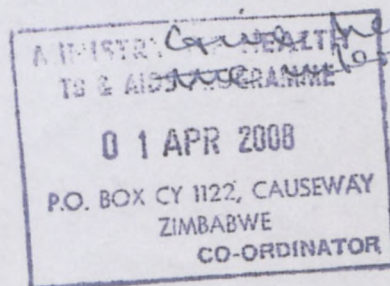
I am a Palliative Care Technical Adviser with Hospice Association of Zimbabwe (HOSPAZ) and involved in Ministry of Health activities. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology (CPUT), South Africa. This requires of me to submit a well-documented research study on *"To Explore to What Extent Palliative Care Needs of Children Clinically Diagnosed with AIDS are Being Met in Harare, Zimbabwe"*. This research study will be carried out at three selected palliative care organizations within Harare.

I would like to seek your permission to conduct an interview with the National Coordinator, AIDS and TB Unit in order to establish the Public Health Sector services available for children with AIDS in Zimbabwe.

Data collection will be done through a structured interview with senior management of the selected organizations. However data collection for this study from the children will be done through an open question and observation in the presence of the manager and parent/guardian to ensure that the rights of the children who are already vulnerable due to illness will be preserved. The data from the children will be collected by Eunice

- No problem

The study is welcome
and has our support.
We will arrange an appointment for
an interview. Thank you



7 September 2007
Ref: CPUT/HAS-REC/0015

P.O. Box 1906 • Bellville 7535 South Africa • Tel: +27 21 442 6162 • Fax +27 21 447 2963
Symphony Road Bellville 7535

**OFFICE OF THE CHAIRPERSON:
HEALTH AND APPLIED SCIENCES RESEARCH ETHICS COMMITTEE (HAS-REC)**

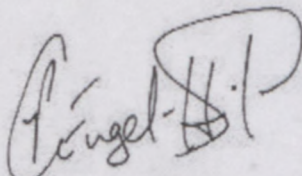
Mrs Eunice Garanganga was granted ethics approval, at the meeting of the HAS-REC on the 7 September 2007, for research activities related to the M Nursing at the Cape Peninsula University of Technology.

TITLE: To explore to what extent the palliative care needs of children clinically diagnosed with AIDS are being met in Harare, Zimbabwe.

Comment:

Research activities are restricted to those detailed in the ethics application dated 31 April 2007 and the revision document dated 5 August 2007.

In line with the MRCZ Approval Letter (Ref: MRCZ/A/1381) ethics approval is valid to 2 May 2008. Should the study continue beyond this date an extension must be requested.



Dr PENELOPE ENGEL-HILLS
CHAIRPERSON: HEALTH AND APPLIED SCIENCES RESEARCH ETHICS COMMITTEE
e-mail: engelhillsp@cput.ac.za

Study title: Palliative Care Needs of Children suffering from AIDS, Zimbabwe

3rd April 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Chair Person
Medical Research Council of Zimbabwe
University of Zimbabwe
Harare

Dear Mrs. Chekera

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) and involved in Ministry of Health activities. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology (CPUT), South Africa. This requires of me to submit a well-documented research study on ***Palliative Care Needs of Children suffering from AIDS, Zimbabwe***. This research study will be carried out at three selected palliative care organizations within Harare.

I would like to seek permission from the Medical Research and Ethics Committee to conduct a research study on Palliative Care needs of children suffering from AIDS, at the three selected palliative care organizations within Harare

Data collection will be done through a structured interview with senior management of the organizations. The data from the children will be through observation. The data from the children will be through observation by Eunice Garanganga, Diploma in palliative care. However informed consent will be obtained from study participants who indicate their willingness to participate in the study without any coercion. Informed consent form is attached. The study will be carried out after ethical approval for the study by the CPUT Health Sciences Research Ethics Committee and the Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated if you could allow me the opportunity to carry out this research for my career advancement and future contribution to the enhancement of national health services. I am conducting the research as a requirement towards obtaining masters in nursing qualification. This is intended specially to inform the Public Health Sector the importance of palliative care needs of children suffering from AIDS.

Thank you

Yours sincerely

Mrs. Eunice Garanganga
Contact details: Tel 263 4 790440 Bus
Mobile 011 218 292

phone: 791792/791193/792747
 fax: (263) - 4 - 790715
 mail: mrcz@mrczimshared.co.zw
 website: <http://www.mrcz.org.zw>



Josiah Tongogara / Mazoe Street
 P. O. Box CY 573
 Causeway
 Harare

MRCZ APPROVAL LETTER

ref: MRCZ/A/1381

Date: 3 May 2007

Mrs Eunice Garanganga
 1 Whitehall Drive
 1. Andrew Park
 Salisbury
 Harare.

E: Palliative Care Needs Of Children Suffering From Aids, Zimbabwe.

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This approval is based on;

- 1) Shona Informed Consent Form
- 2) English informed Consent Form
- 3) Study Protocol
- 4) Participant Information Sheet (Shona and English) Annexure 6.

APPROVAL NUMBER : MRCZ/A/1381

This number should be used on all correspondence, consent forms and documents as appropriate.

APPROVAL DATE : 3 May, 2007

MRCZ MEETING DATE : 3 May, 2007

TYPE OF MEETING : FULL BOARD

EXPIRATION DATE : This approval expires on 2 May 2008.

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review

SERIOUS ADVERSE EVENT REPORTING : All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.

MODIFICATIONS: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents)

TERMINATION OF STUDY: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.

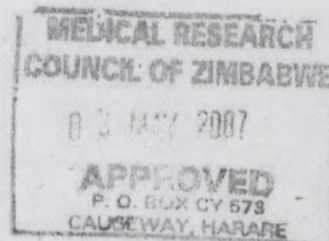
QUESTIONS: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrczimshared.co.zw.

Other:

Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database

Kind regards from the MRCZ Secretariat.

[Handwritten signature]



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
 (IRB Number IRB00002409 IORG0001913)

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

5th August 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Chair Person
Medical Research Council of Zimbabwe
University of Zimbabwe
Harare

Dear Mrs. Chekera

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) and involved in Ministry of Health activities. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology (CPUT), South Africa. This requires of me to submit a well-documented research study. I would like to inform you that I have changed the study title from '*Palliative Care Needs of Children Suffering from AIDS, Zimbabwe*' to "**To Explore to What Extent the Palliative Care Needs of Children Clinically Diagnosed with AIDS are Being Met in Harare, Zimbabwe**"

I would like to seek permission from the Medical Research and Ethics Committee to conduct a research study to explore to what extent palliative care needs of children clinically diagnosed with AIDS are being met in urban and peri-urban areas of Harare in Zimbabwe. The study will be conducted at three selected palliative care organizations within Harare. Attached are the letters of permission from the three NGO organizations.

Data on palliative care for children with clinically diagnosed with AIDS will be obtained through structured interviews with National Coordinator AIDS and TB Unit, Ministry of Health and Child Welfare and managerial personnel of the three selected care organisations.

I recognise that children are a vulnerable population in research and health care. This research is undertaken with this understanding in mind. It is important to get the children themselves what they perceive to be their needs when they are sick. Information will be obtained in non-threatening way and being sensitive to their health status and the fact that they are minors. An open question is asked with no promises made, (**Annexure 5**). Unstructured data collection refers to responsive, flexible and interactive questioning techniques used in in-depth data collection. However field notes from observation will provide an opportunity to record what the researcher sees and hears outside the immediate context of the interview.

The data from the children will be collected by Eunice Garanganga, Diploma in palliative care and BSC Counselling. Informed consent will be obtained from study participants, parents/guardians who indicate their willingness to participate in the study without any coercion.

Informed consent form is attached. In addition the researcher will seek the agreement of the children or obtain assent, recognizing the child's age and maturity, to participate in the study before information is collected. Ethical considerations, (**Annexure 12**) attached. The study will be carried out after ethical approval for the study by the CPUT Health Sciences Research Ethics Committee and the Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated if you could allow me the opportunity to carry out this research for my career advancement and future contribution to the enhancement of national health services. The study has potential to make an important and relevant contribution to palliative care of children with HIV and AIDS. This is intended specially to inform the Public Health Sector, NGOs and the community of services of palliative care health needs of children clinically diagnosed with AIDS.

Thank you

Yours sincerely

Mrs. Eunice Garanganga
Contact details: Tel 263 4 2900369, 790440 Bus
Mobile 263 11 218 292

Telephone: 791792/791193/792747
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrczimsahred.co.zw



Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

Ref: MRCZ/A/1381

21 August 2007

Mrs Eunice Garanganga
21 Whitehall Drive
St Andrew Park
Mabel reign
Harare

RE: Amendment of Study Title "Palliative Care Needs of Children Suffering from AIDS, Zimbabwe" to- "To Explore to What Extend The Palliative Care Needs of Children Clinically Diagnosed With AIDS Are Being Met in Harare, Zimbabwe"

We refer to your correspondence dated 5 August 2007 on the above subject.

Please be advised that the Medical Research Council has no objections to the changes made to the title .

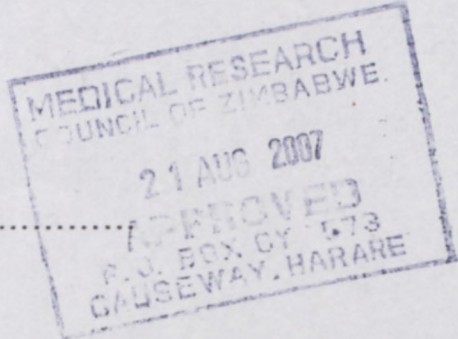
Thank you for the notification of the amendment.

Sincerely

Rickera

R. Chekera
For Chairperson

MEDICAL RESEARCH COUNCIL OF ZIMBABWE





Telephone: 791792/791193
 Telefax: (263) - 4 - 790715
 E-mail: mrcz@mrczimshared.co.zw

Medical Research Council of Zimbabwe
 Josiah Tongogara / Mazoe Street
 P. O. Box CY 573
 Causeway
 Harare

CONTINUING REVIEW APPROVAL

Ref: MRCZ/A/1381

Date 25 April 2008

Mrs. Eunice Garanganga
 21 Whitehall Drive
 St. Andrew Park
 Malbereign
Harare

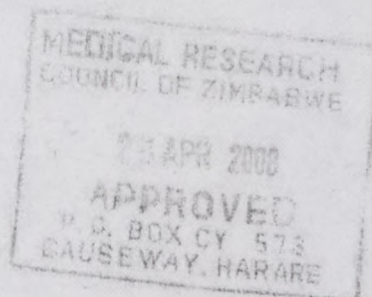
RE: To Explore to What Extent The Palliative Care Needs of Children Clinically Diagnosed With AIDS Are Being Met in Harare, Zimbabwe (previously called 'Palliative Care Needs of Children Suffering From AIDS, Zimbabwe').

Thank you for the Application for Continuing Review of Research Activity and Progress Report that you submitted for review to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to continue conducting the above titled study. This is based on the **review** and **approval** of the following documents that were submitted to the MRCZ for review.

- Completed MRCZ 102 Form
- A Progress report
- Adverse Event Summary Table
- **APPROVAL NUMBER** :MRCZ/A/1381
 This number should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL EFFECTIVE DATE** : 3 May 2008
- **MRCZ MEETING DATE** : 24 April 2008
- **EXPIRATION DATE** : 2 May 2009
- **TYPE OF MEETING** : Full Board
 After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrczimshared.co.zw.
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Kind regards from the MRCZ Secretariat.

Dreica



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
 Number IRB00002409 IORG0001913

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

Participant Information Sheet

RESEARCH: The purpose of this study is to explore to what extent palliative care needs of children clinically diagnosed with AIDS are being met in urban and peri-urban areas of Harare in Zimbabwe.

AIM OF THE RESEARCH

The aim of this study is to explore to what extent palliative care needs of children clinically diagnosed with AIDS are being met in urban and peri-urban areas of Harare in Zimbabwe. It will establish the services available for children clinically diagnosed with AIDS in order to inform the Zimbabwe Public Health Sector, NGOs and community of services of palliative health care needs of children

RISKS AND BENEFITS

There are no risks that the researcher is aware of if you participate in this research. However you might feel uncomfortable being observed. There are no direct benefits to you. However, it will benefit the Zimbabwe Public Health Sector, NGOs and community as the research results can influence or direct future provision of palliative care for children for better quality of care. It has potential to make an important and relevant contribution to palliative care of children with HIV and AIDS. It can also be used in favour of children to have support and resources that can improve their care. Participants will not be paid for their participation in this study.

PRIVACY AND CONFIDENTIALITY

All the information that is obtained from you during the research process will be kept confidential by the principal researcher, who will limit or control the research from favouring participants without examining the facts fully. Your privacy will be protected. The information will be arranged in a special system that will not allow the identification of individual participants, and this ensures that information from you will not be linked with you or lead anyone to identify you. The information will be kept and used for references and important checks. Parents or guardians and children will be free to withdraw from participating in the study at any time and still receive standard care. Should this occur, the information will be torn and destroyed in the presence of the parent or guardian and child, and the information gathered will be excluded from the data for analysis.

FEEDBACK TO PARTICIPANTS REGARDING STUDY RESULTS

If you like to be informed of the study results, a copy of the research findings will be available at the organisation where you are receiving care.

CONTACT DETAILS

You are welcome to talk to me during and after data collection if necessary. My contact details in Harare are: telephone 263 4 2900369 or 790440; 263 11 218292

Vernacular Participant Information

Tsanangudzo yeongororo yekuchengetwa kwemhando yepamusoro vana vanorwara ne Mukondombera takanangana nekupedza marwadzo muviri, pfungwa, mweya nemagariro mu Zimbabwe (Palliative Care)

Tsanangudzo neruzivo kune vanoda kupinda muongororo iyi

Ongororo iyi iri kutswaga nekutarisa zvinodiwa, pakuchengeta vana vanorwara nemukondombera muZimbabwe. Inoongororazve maitirwo (masevisi) nemarapirwo aripo iye zvino anoitwa vana vanorwara nemukondombera.

Paongororo iyi hapana pfumvu kana njodzi dzinozivikanwa neni ndiri kuita tsvagiridzo yacho, dzinogona kukanganisa upenyu hweavo vachapinda muongororo. Zvisinei hazvo, vamwe havana kusununguka kupindura mibvunzo yakanangana nekuchengetwa kwavo.

Hapana mubairo kana muripo unopiwa avo vanenge vapinda mutsvagiridzo iyi. Asi kuti zvichabuda muongororo iyi zvichabatsira Bumbiro re zve Utano (Ministry of Health and Child Welfare muZimbabwe), mapato akazvimirira (maNGO), uye nenharaunda yese, kuitira kuti vana vanorwara nemukondombera vachengetwe nekurapwa zvakanaka

Zvose zviru maererano nezvenyu zvichabva kwamuri paongororo hazvishambadziwi kuvanhu, ndichazvichengetedza chaizvo setsindidzo. Munogona kubuda mutsvagiridzo iyi kana musisadi kuenderera mberi nayo. Uyezve hazvina chakashata chinoitwa kwamuri kana mwana. Rubatsiro nekuchengetwa kuri kuitwa mwana wenyu hakushanduki kunoramba kuchienderera mberi mune zvakanaka. Kana zvichinge zvaita saizvozvo mapepa anotaura nezvenyu anobva apiswa.

Kana muchida kuziva zvinobuda muongororo iyi, munozviwana kuNGO kana bato riri kukupayi rubatsiro rwekuchengeta mwana.

Kana muine mibvunzo munogona kutaura neni. Munondibata muHarare parunhare runoti 263 4 2900369; 263 11 218292.

Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

Informed Consent form

CONSENT TO TAKE PART IN THE STUDY, PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

Thank you for agreeing to participate in this study to explore to what extent palliative care needs of children clinically diagnosed with AIDS. I would like to confirm that you understand the explanation on the participant information sheet and what I have explained regarding the study, what it involves, by signing the participant section.

The information obtained from the interviews and observations during the study will be kept confidential. You may ask questions for further clarification.

This confirms that I,....., parent / guardian of the child receiving palliative care, declare of my free will, that the care of the child under my care, be explored through interview and observation by the researcher as part of this study.

Parent / Guardian name: _____

Signature: _____

Date: _____

I,, hereby confirm that the above parent / guardian has been informed about the nature of this study.

Researcher's name: Mrs. Eunice Garanganga

Signature: _____

Date: _____

Vernacular Informed Consent

Tsanangudzo yeongororo yekuchengetwa kwemhando yepamusoro vana vanorwara ne Mukondombera takanangana nekupedza marwadzo muviri, pfungwa, mweya nemagariro mu Zimbabwe (Palliative Care)

Kubvuma paine ruzivo ne tsanangudzo yakakwana (Informed Consent)

Kubvuma kupinda muongororo yekutarisa zvinodiwa pakuchengeta vana vanorwara nemukondombera muZimbabwe.

Ndinotenda nekubvuma kwenyu musina kumbunyikidzwa kuti ndiongorore nekutarisa machengeterwo ari kuitwa mwana wenyu. Ndiri kuda kuziva kana muchiri kuyeuka zvandakakutsanangurirai nezveongororo iyi, uyezve zviri parugwaro rwandakakupayi.

Ndinodzokororazve kukuzivisayi kuti zvose zvandichawana kwamuri nemwana ndinozvichengeta setsindidzo

Munosaina zita renyu kana muri kuwirirana nazvo.

Ini.....mubereki/muchengeti wemwana ari kuwana kuchengetwa kwemhando yepamusoro (Palliative Care) ndinobvuma semubereki/muchengeti wemwana kuti rubatsiro rwaari kuwana rutariswe nemunhu ari kuita ongororo kana tsvagiridzo iyi. Uyezve ndinobvuma kuti muzvare Eunice Garanganga akukurukure nemwana pakuongorora kwake

Zita rangu.....

Kusaina (siginecha).....

Dheti

Ini muzvare Eunice Garanganga ndinovimbisa kuti mubereki/muchengeti wemwana asaina aine ruzivo rwakakwana pamusoro petsvagiridzo yandichaita kuvana vanorwara ne mukondombera.

Zita rangu: Muzvare Eunice Garanganga

Kusaina (Siginecha).....

Dheti.....

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

3rd April 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Director
Mashambanzou Care Trust
Waterfalls
Harare

Dear Sister Margaret

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ), the umbrella body for palliative and home based care organizations in Zimbabwe. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology, South Africa. This requires of me to submit a well-documented research study on ***"PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE"***

I would like to seek your permission to conduct a research on services provided for children clinically diagnosed with AIDS in your organization. I would also like to seek your permission to conduct an interview with the Manager who is responsible for the provision of care for children and families. The purpose of this study is to explore to whether palliative care needs of children diagnosed with AIDS are being met in Harare, which can be shared and exchanged for the improvement of future quality of care for the children.

Data collection will be done through a structured interview with senior management of your organization. However data collection for this study from the children will be done through an open question and observation in the presence of the manager and parent/guardian to ensure that the rights of the children who are already vulnerable due to illness will be preserved. The data from the children will be collected by Eunice Garanganga; RN, BSc Counselling, Diploma in Palliative Care. Informed consent will be obtained from the participants who are voluntarily willing to participate in the study. Assent will be obtained from the children. The study will **only** be carried out after ethical approval for the study, by the Health Sciences Research Faculty Committee and the Research Ethics Committee situated in the Cape Peninsula University of Technology and Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated, if you could allow me the opportunity to carry out this research in your organization. I am conducting the research as a requirement towards obtaining masters in nursing qualification. The research results are intended to contribute to future developments of palliative care for children in Zimbabwe.

Thank you

Yours sincerely

Mrs. Eunice Garanganga

Contact details:

Tel 263 4 2900369 Bus

Mobile 011 218 292

Fax 263 4 705775



Mashambanzou

40 Sandown Road, Waterfalls,
Harare, Zimbabwe

Tel/Fax: +263 (0)4 610937 Tel: +263 (0)4 610079
WO 9/90

Email : mashamba@mweb.co.zw

Web : www.geocities.com/mashambanzoucaretrust

17th April 2007

Mrs Eunice Garanganga
21 Whitehall Drive
Mabelreign
HARARE

Dear Mrs Garanganga

RESEARCH STUDY ON PALLIATIVE CARE NEEDS

Sr Margaret Mc Allen has referred to me your letter, dated 03rd April 2007, for a response.

Your application for permission to conduct research on services provided for children suffering from AIDS is approved. Permission is also granted to conduct an interview with the officer responsible for the provision of care for vulnerable children. This permission is given subject to the following terms and conditions:

1. You will not be allowed to take any photographs/films or tape recorded interviews or sessions of our clients, and,
2. Any information gathered or which comes to your knowledge through your attachment to our organization must not be used for any other purposes other than for your post graduate course with the Cape Peninsula University of Technology, South Africa, and,
3. You will observe the requirements of client confidentiality and or Mashambanzou values, and,
4. You will submit, and before the commencement of the study, 'The Ethical Approval for the Study' from the Health Sciences Research Faculty Committee and The Research Ethics Committee and as indicated in your letter, and,
5. You will avail us of any interview questionnaires for our approval and well in advance, and,
6. You will report directly to our projects officer, during the period of your study, who may issue you with further terms and conditions, and
7. You will avail us with a copy of your report immediately upon completion of your research.

Enclosed please find a copy of this letter for your signature and return and in acknowledgement of your agreement to the above noted terms and or conditions.

Yours sincerely

Henry Masaya
HUMAN RESOURCES & ADMIN OFFICER

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

3rd April 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Director
New Dawn of Hope
Mufakose
Harare

Dear Mr. E Chikukwa

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ), the umbrella body for palliative and home based care organizations in Zimbabwe. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology, South Africa. This requires of me to submit a well-documented research study on "**PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE**"

I would like to seek your permission to conduct a research on services provided for children clinically diagnosed with AIDS in your organization. I would also like to seek your permission to conduct an interview with the Manager who is responsible for the provision of care for children and families. The purpose of this study is to explore to whether palliative care needs of children diagnosed with AIDS are being met in Harare, which can be shared and exchanged for the improvement of future quality of care for the children.

Data collection will be done through a structured interview with senior management of your organization. However data collection for this study from the children will be done through an open question and observation in the presence of the manager and parent/guardian to ensure that the rights of the children who are already vulnerable due to illness will be preserved. The data from the children will be collected by Eunice Garanganga; RN, BSc Counselling, Diploma in Palliative Care. Informed consent will be obtained from the participants who are voluntarily willing to participate in the study. Assent will be obtained from the children. The study will **only** be carried out after ethical approval for the study, by the Health Sciences Research Faculty Committee and the Research Ethics Committee situated in the Cape Peninsula University of Technology and Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated, if you could allow me the opportunity to carry out this research in your organization. I am conducting the research as a requirement towards obtaining masters in nursing qualification. The research results are intended to contribute to future developments of palliative care for children in Zimbabwe.

Thank you

Yours sincerely

Mrs. Eunice Garanganga

Contact details:

Tel 263 4 2900369 Bus

Mobile 011 218 292

Fax 263 4 705775



10 MUUYU LANE
MUFAKOSE
HARARE

P.O. BOX MFE94
MUFAKOSE
HARARE
TELEFAX: 04 698447
Email: newdawnofhope@zol.co.zw

DEED OF TRUST NO. MA354/2005

19/04/07
Head of Department
Cape Peninsula University of Technology
Cape Town
South Africa

Dear Sir/Madam

RE: PERMISSION TO CARRY OUT RESEARCH: EUNICE GARANGANGA

This letter serves to certify that Eunice Garanganga has been given permission to carry out a Research Project on *Palliative Care Needs of Children Suffering from AIDS, Zimbabwe* with New Dawn of Hope.

The organisation pledges to give her all possible support in the carrying out of this project.

We have worked with Eunice before and we are convinced that she will conduct the project with the highest considerations for professionalism and ethics.

Yours faithfully

E. Chikukwa
DIRECTOR

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

3rd April 2007

21 Whitehall Drive
St Andrew Park
Mabelreign
Harare

The Director
Seke Rural HBC
Seke
Harare

Dear Mrs. V. Ngwerume

I am a Palliative Care Technical Adviser with Hospice and Palliative Care Association of Zimbabwe (HOSPAZ), the umbrella body for palliative and home based care organizations in Zimbabwe. I write to inform you that I am currently doing a postgraduate course at Cape Peninsula University of Technology, South Africa. This requires of me to submit a well-documented research study on ***"PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE"***

I would like to seek your permission to conduct a research on services provided for children clinically diagnosed with AIDS in your organization. I would also like to seek your permission to conduct an interview with the Manager who is responsible for the provision of care for children and families. The purpose of this study is to explore to whether palliative care needs of children diagnosed with AIDS are being met in Harare, which can be shared and exchanged for the improvement of future quality of care for the children.

Data collection will be done through a structured interview with senior management of your organization. However data collection for this study from the children will be done through an open question and observation in the presence of the manager and parent/guardian to ensure that the rights of the children who are already vulnerable due to illness will be preserved. The data from the children will be collected by Eunice Garanganga; RN, BSc Counselling, Diploma in Palliative Care. Informed consent will be obtained from the participants who are voluntarily willing to participate in the study. Assent will be obtained from the children. The study will **only** be carried out after ethical approval for the study, by the Health Sciences Research Faculty Committee and the Research Ethics Committee situated in the Cape Peninsula University of Technology and Medical Research Council in Harare, Zimbabwe.

It would be of great assistance and mostly appreciated, if you could allow me the opportunity to carry out this research in your organization. I am conducting the research as a requirement towards obtaining masters in nursing qualification. The research results are intended to contribute to future developments of palliative care for children in Zimbabwe.

Thank you

Yours sincerely

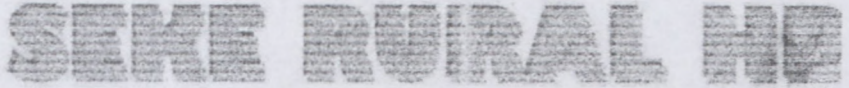
Mrs. Eunice Garanganga

Contact details:

Tel 263 4 2900369 Bus

Mobile 011 218 292

Fax 263 4 705775



Palliative Care, Bereavement & Orphan Care

Kanaka Hospital
Deans Growth Point

PO Box 511 180
Seke, Zimbabwe

Fax: 203-0
Cell: 023 411 689 or 01

5 April 2007

The palliative Care Technical Adviser
HOSPAZ

Dear Mrs Garanganga

**RE: PERMISSION TO CONDUCT A RESEARCH ON SERVICES PROVIDED
FOR CHILDREN SUFFERING FROM AIDS.**

This letter serves to grant you permission to carry out your research on the services provided for children suffering from AIDS by Seke Rural Home Based Care. It is our hope that the organisation can provide essential information which will be used to improve the lives of children infected by the virus.

You can conduct your interview with our Palliative Care Nurse. Kindly share with us the findings of this research.

Yours sincerely

V. Ngwerume
DIRECTOR

Annexure 6

Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

Structured interview with the National Coordinator, AIDS and TB Unit, Ministry of Health and Child Welfare, to be conducted at the Ministry of Health Department to obtain information on services offered to children diagnosed with AIDS.

Name of Institution.....

Designation of person(s) interviewed.....

Date..... Time: From..... To.....

1. What type of services is offered to children clinically diagnosed with AIDS in the public health sector at Tertiary, Provincial and District level?

Palliative care indicator guide	Tertiary	Provincial	District
What is available for pain management
WHO analgesic ladder
Step 1 for mild pain
Step 2 for moderate pain
Step 3 for severe pain
Essential Drug List

Palliative care indicator guide	Tertiary	Provincial	District
<p>Are symptoms managed</p> <p>Management of Opportunistic Infections</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
<p>Provision of ART</p> <p>Provision of prophylaxis eg cotrimoxazole</p> <p>Treatment of OIs</p> <p>Provision of symptom management related to ART</p> <p>Management of side effects related to ART medicines</p> <p>Use of referral system</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

Palliative care indicator guide	Tertiary	Provincial	District
Information sharing Are carers provided with information relating to care of the sick
Food security

Out of Hospital

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Thank you for your participation.

Mrs. Eunice Garanganga
Contact details:
Tel 263 4 2900369 Bus
Mobile 263 11 218 292

Annexure 7

Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

Structured interview with a person in a managerial position, to be conducted on site to obtain background information on organizations selected for inclusion into study

Name of Organization/Institution:

Designation of person interviewed:

Date: Time: From: To:

NGO: Faith-based:

1. Please indicate your health care worker compliment, i.e. nurses, care givers, doctors, and/or social workers.

Health care worker	M	F	Palliative care trained	Full time	Part time	Voluntary	In patient	HBC
Nurse								
S/worker								
Doctor								
Caregiver								

Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

Palliative Care Indicator Guide

Five key areas of palliative care have been identified for measurement: pain and symptom relief; access to drugs; emotional / spiritual support and grief counseling; support for family carers; and family-based advanced care planning. However HIV –related Palliative Care is grouped in four categories: Clinical/Physical Care, Psychological Care, Spiritual Care, and Social Care (Hearn & Higginson 1999; 8: 219-27)

INDICATORS

<p>CLINICAL/PHYSICAL Assessment of pain</p> <p>Pain management, following WHO analgesic ladder Step 1 for mild pain</p> <p>Step 2 for moderate pain</p> <p>Step 3 for severe pain</p>	<p>Assessment of symptoms screening, assessment, care, and treatment with appropriate relieving medications or therapies</p> <p>Management of opportunistic infections</p>	<p>Drug Availability Access to essential palliative care drugs</p> <p>Access to ARVs</p>
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INDICATORS

<p>PSYCHOLOGICAL CARE</p> <p>Screening and assessment of emotional problems related to HIV disease</p> <p>Provision of emotional support and counseling</p> <p>Participation in support groups</p>	<p>SPIRITUAL CARE</p> <p>Screening and assessment of spiritual problems related to HIV disease</p> <p>Preparing for and coping with death and dying process</p> <p>Provision of counseling related to hopes, fears, meaning and purpose, guilt and forgiveness</p>	<p>SOCIAL CARE</p> <p>Screening and assessment of social problems related to HIV disease</p> <p>Creation of linkages and referral system, e.g. school, nutrition security, support groups or other interventions</p> <p>Provision of counseling for client and family related to losses</p> <p>Provision of care and support for carers (family caregivers taking care of a child at home)</p>
<p>INFORMATION GIVING AND SHARING</p> <p>Information giving for carers on e.g. Treatment and medication, universal precaution, basic nursing care such as bathing and feeding patient</p> <p>On illness and prognosis</p> <p>Available support systems</p>		

**Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS,
ZIMBABWE**

The APCA (African Palliative Care Association) African POS (Palliative Outcome Scale)

The 5 domains of palliative care for quality measurement are: **Physical; Emotional; Spiritual; Information received; Family support**

Pain and symptoms are relieved:

- patients receive relief of pain
- patients receive relief of symptoms

Have access to essential palliative care drugs including ART

- patients receive prescribed drugs including ART
Note: prescribed drugs include both drugs per prescription as well as those purchased over the counter (OTC)

Emotional and spiritual support and grief counselling provided

- families receive emotional and spiritual support
- patients receive emotional and spiritual support
- families receive bereavement support during illness and after death of the patient

Support for family caregivers taking care of a patient at home

- "family" caregivers receive support in caring for the patient at home

Increased proportion of families and patient receiving support for planning for the future

- families within the programme receive support in planning for the future
- patient within the programme receive support and included in planning for the future
- patients and families referred from the programme to other programmes for further support
- patients and families receive information for advance planning

Study title: PALLIATIVE CARE NEEDS OF CHILDREN SUFFERING FROM AIDS, ZIMBABWE

WHO Pediatric Clinical Staging: four HIV/AIDS stages.

STAGE 1
Asymptomatic Persistent generalized lymphadenopathy (PGL) Hepatosplenomegaly
STAGE 2
Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis, 2 or more episodes in any 6 month period) Papular pruritic eruptions Seborrhoeic dermatitis Extensive Human papilloma virus infection or Molluscum infection (more than 5% body area or disfiguring) Herpes zoster (1 or more episodes in 6 months) Fungal nail infections Recurrent oral ulcerations (2 or more episodes in 6 months). Lineal Gingival Erythema (LGE) Angular cheilitis Parotid enlargement
STAGE 3
Conditions where a presumptive diagnosis can be made using clinical signs and simple investigations Unexplained moderate malnutrition not adequately responding to standard therapy Unexplained persistent diarrhoea (more than 14 days) Unexplained persistent fever (intermittent or constant, for longer than 1month) Oral candidiasis (outside neonatal period) Oral hairy leukoplakia Acute necrotizing ulcerative gingivitis/periodontitis Pulmonary tuberculosis Severe recurrent presumed bacterial pneumonia (2 or more episodes in 6 months)
STAGE 4
Conditions where a presumptive diagnosis can be made using clinical signs or simple investigations: Unexplained severe wasting or severe malnutrition ¹ not adequately responding to standard therapy Pneumocystis pneumonia Recurrent severe presumed bacterial infections (2 or > episodes within one year e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia) Chronic orolabial or cutaneous Herpes simplex infection (of more 1 month duration) Extrapulmonary tuberculosis Kaposi's sarcoma Oesophageal Candida CNS Toxoplasmosis HIV encephalopathy Conditions where confirmatory diagnostic testing is necessary.

Source: World Health Organization (WHO). 2004. Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach, 2003 Revision.

