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The Impact of Palliative Care on Health Status in HIV-Positive Children

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2017

Abstract

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M. B.Ch. B., University of Nairobi, 2005

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Abstract

HIV-positive children in sub-Saharan Africa have numerous challenges to overcome. These challenges increase psychosocial stress as well as symptom burden including fatigue, weight loss, pain, and mental changes. The symptoms may persist even after initiation of antiretroviral therapy, so such children need additional care. Palliative care lays emphasis on holistic patient-centered care, including physical, psychological, social, and spiritual symptoms, alongside antiretroviral therapy. There is limited data on the impact of integrating palliative care with standard HIV care and treatment in children. The purpose of this study was to fill the gap in the literature by investigating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. The theoretical framework was based on the humanistic nursing theory. Using the Mann Whitney U and logistic regression tests, the health-related quality of life of 97 children who received palliative care in addition to standard HIV care was compared to 180 HIV-positive children who received standard HIV care only through chart reviews. According to study results, children receiving palliative care alongside antiretroviral therapy have better physical and psychosocial health compared to children receiving only antiretroviral therapy. Increasing age was a contributing factor to better psychosocial and physical health in patients receiving palliative care. Emotional, social, and school functioning are important factors that determine treatment outcomes in children on antiretroviral therapy, and addressing those factors through palliative care will create a positive social change by improving treatment outcomes, quality of life, and longevity.

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Dedication

I dedicate this dissertation to all those children who have been inflicted by the HIV virus living in Kenya and across the globe.

Acknowledgments

I wish to thank Dr. Vasileios Margaritis for being a wonderful chair of my committee. His guidance has made this possible. I also wish to thank my committee member, Dr. Aaron Mendelsohn, and my URR member, Dr. Michael Furukawa, for their support in the preparation of this document. I appreciate the advice I received from Dr. Hellen Kariuki, Dr. Eva Namisango, and last but not the least, Dr. Richard Harding.

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Chapter 1: Introduction to the Study

Background Information

There are more than 33 million people infected with HIV worldwide (Avert, 2014). Fifty percent of these are women, and 3.3 million are children (Avert, 2014). The number of new HIV infections worldwide in a year is about 2.5 million in adults and 330,000 in children (Avert, 2014). The number of global deaths due to HIV is about 1.7 million in adults and children (Avert, 2014). Greater than 90% of the world's HIV-positive pediatric population lives in sub-Saharan Africa (Harding et al., 2014).

The number of individuals living with HIV and AIDS has been on the rise worldwide (Fan et al., 2011). HIV continues to remain a major cause of morbidity and mortality in children, particularly in sub-Saharan Africa (Connor et al., 2014). In 2003, the United States funded the President's Emergency Plan for AIDS Relief (PEPFAR) to fight the AIDS epidemic (Harding et al., 2014). PEPFAR is an initiative of the USA to fund the provision of antiretroviral therapy to countries most affected by HIV (United States President's Emergency Plan for AIDS Relief, 2016). In subsequent years, the funding of PEPFAR increased by more than three times the original amount of $15 billion (Harding et al., 2014). An evaluation of PEPFAR revealed that the goals of initiating individuals on antiretroviral therapy are met (Harding et al., 2014). However, there has been no study to evaluate the overall operation and implementation of comprehensive programs that include palliative care as an integral component (Harding et al., 2014).

HIV-positive children in sub-Saharan Africa have numerous challenges to overcome. Such burdens include the responsibility of caring for other HIV-positive family members and taking up the financial requirements of the family (Connor et al., 2014). Not only does this increase the psychosocial stress on HIV-positive children but it also increases symptom burden including fatigue, weight loss, pain, and mental changes (Harding et al., 2014). Such symptoms may persist even after initiation of antiretroviral therapy (Harding et al., 2014). Immune reconstitution syndrome after initiation of antiretroviral therapy worsens their condition (Harding et al., 2014).

In South Africa, hospitalized children have been noted to report discomfort; distress; and pain from physical illness, HIV stigmatization, and stressful social and economic circumstances (Ritcher et al., 2009). Sub-Saharan Africa is also faced with the additional challenges of overburdened hospitals and lack of specialized health care providers (Ritcher et al., 2009). HIV-positive children in such settings require attention to their cognitive, motor, and social development (Ritcher et al., 2009). Poor adherence to antiretroviral drugs is yet another challenge faced in sub-Saharan Africa (Loefler, 2002). Such factors limit the virologic and immunologic responses to antiretroviral therapy and worsen morbidity.

The advent of antiretroviral therapy has led to improved access to medication (Harding et al., 2014). However, this has led to further increase in demand for palliative care services such as pain reduction and management of adverse effects related to antiretroviral treatment (Connor et al., 2014). Although the scale-up of antiretroviral therapy has been rapid, the growth in the provision of palliative care has not been commensurate with the demand for such services (Connor et al., 2014).

Needs assessments of palliative care have been carried out in Zimbabwe, South Africa, Uganda, and Kenya (Connor et al., 2014). Such needs include physical, social, psychological, and spiritual care (Nakawesi et al., 2015). While the palliative care needs of HIV-positive children are similar to those of children with cancer, it should be kept in mind that HIV-positive children in developing countries have a myriad of challenges that they have to overcome that children with cancer necessarily do not (Harding et al., 2014). Best practices in palliative care in adults have also been appraised (Harding et al., 2010). However, there has been little progress in pediatric palliative care provision (Connor et al., 2014).

HIV-positive children receiving hospice care as part of comprehensive care have some of their palliative care needs addressed (Lyon et al., 2008). Baseline characteristics of such children show that they had low quality of life scores compared to the general population (Lyon et al., 2008). However, a relatively low number of children have been enrolled for palliative care even in such settings where hospice care is provided (Lyon et al., 2008). The family-centered approach (FACE) has also been tested in some HIV settings (Dallas et al., 2012). Testing of the long-term efficacy of such an approach on the congruence on end of life management would be important.

The longitudinal follow-up of adults receiving palliative care in a randomized controlled trial has been conducted in Kenya and has shown benefits in quality of life of adults (Lowther et al., 2014). Baseline characteristics and some treatment outcomes, such as reduction in stress, have been demonstrated in children (Lyon et al., 2008). An assessment of the impact of palliative care on health status in HIV-positive children receiving antiretroviral therapy could reveal empirical evidence on treatment outcomes and quality of life.

Problem Statement

Despite antiretroviral initiation, people living with HIV and AIDS continue to suffer symptom burden (Campos, Cesar, & Guimaraes, 2009; Fan, Kuo, Kao, Morisky, & Chen, 2011; Harding, Molloy, Easterbrook, Frame, & Higginson, 2006; Willard et al., 2009). People living with HIV/AIDS have a higher burden of physical problems compared with the HIV-negative population (Harding & Sherr, 2014; Parker, Stein, & Jelsma, 2014). The prevalence of anxiety and depression is higher among HIV-positive people than in the general population as well as populations with other chronic conditions such as renal failure or cancers (Lowther, Harding, Selman, & Higginson, 2014). While this compromises quality of life of individuals living with HIV/AIDS, it also threatens the continued success of the roll out of antiretroviral therapy due to the association of depression and distress arising as a result of antiretroviral toxicity (Braithwaite et al., 2008) and poorer treatment outcomes (Gonzalez, Batchelder, Psaros, & Safren, 2011).

Palliative care lays emphasis on holistic patient-centered care, including the impact of illness on the family and recognition of the importance and interdependence of physical, psychological, social, and spiritual symptoms alongside antiretroviral therapy (World Health Organization [WHO], 2006). There is a paucity of evidence from low and middle-income countries and a lack of research evidence of the impact of integrating palliative care into standard HIV care alongside treatment since the advent of antiretroviral therapy (Harding et al., 2005). Integrating palliative care could have positive pain reduction outcomes in people living with HIV/AIDS (Green et al., 2010). Lowther et al. (2012) used a mixed methods approach to show the positive impact of palliative care on treatment outcomes in Kenya and South Africa. While these isolated studies have been conducted on adult patients, there is little or no evidence to demonstrate treatment outcomes for children receiving palliative care alongside antiretroviral therapy (Harding et al., 2014).

Purpose Statement

The purpose of this study was to fill the gap in the existing literature by demonstrating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. I conducted the study in Mombasa, Kenya, which is a low-income setting (WHO, 2014). The research approach was that of a quantitative mode. I conducted a chart review of children who had been initiated on palliative care and compared their health scores to those children who received standard HIV care and treatment but without palliative care.

Research Question and Hypotheses

The following research questions (RQs) guided this study:

RQ1: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only?

$H_0$1a: There is no significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1a: There is a significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only

$H_0$1b: There is no significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1b: There is a significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

$H_0$1c: There is no significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1c: There is a significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

RQ2: Is there a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only?

$H_0$2: There is no significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A2: There is a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

RQ3: Is there a difference in psychosocial health and physical health between children on antiretroviral therapy who receive palliative care and those who do not receive palliative care when controlled for age, gender, duration on antiretroviral therapy, and cluster of differentiation 4 (CD4) count?

$H_0$3: There is no significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count

H_A3: There is a significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count

Theoretical Framework

In pediatric HIV care, the primary contact person for the child and the parent is the nurse (Lowther et al., 2014). Hence, a nurse-led approach in providing palliative care would be appropriate (Lowther et al., 2014). Nursing can be viewed as standing between ontological and epistemological crossroads (Mulholland, 1994). One is a positive paradigm closely related to an illness-cure model while the other is a phenomenologically informed humanistic paradigm related to a health care model (Mulholland, 1994). The choice is thus between an illness-cure model and a humanistic path. The inclination towards the humanistic path is justified because it enables nurses to meet the diverse individual needs of a differentiated population (Mulholland, 1994).

Hospice and palliative care find their roots in comfort and compassionate care for persons who suffer a life-limiting illness (Wu & Volker, 2012). Hence, Kolcaba and DiMarco (2005) proposed a comfort theory for palliative care with an emphasis on physical, psychospiritual, sociocultural, and environmental aspects of comfort—holistic comfort care for patients. The tenets of comfort theory can, in turn, be traced to the humanistic nursing theory proposed by Paterson and Zderad in the early 1960s (McCamant, 2006). The humanistic theory continued to evolve in the next few decades. According to this theory, nursing is described as a human response by one person to another person in need (Wu & Volker, 2012). The theory thus goes beyond describing nursing as a profession or even a calling. The lived experience of nursing can be considered a source of knowledge (McCamant, 2006). Thus, according to this theory, total nursing is described in all contexts and hence is considered a meta-theory (Wu & Volker, 2012).

The act of nursing has to be understood regarding both the patient and the nurse. Such a relationship is characterized by interactions designed to promote well-being and existential growth in the lived world (McCamant, 2006). Nursing is thus viewed as an intersubjective dialogue and transaction that includes meetings and presence in a world of people, things, time, and space (Wu & Volker, 2012). The nurse and the patient are two unique individuals meeting for the same goal – wellbeing. When a nurse responds to a patient's need, there is a transaction between the nurse and the patient (McCamant, 2006). In such a transaction, the nurse and the patient are interdependent and free to know and interact with each other (Wu & Volker, 2012).

The philosophical perspectives of the humanistic nursing theory apply to the practice of palliative care that also focuses on holistic care, open discussions between the nurse and the patient, and emphasizing the unique relationship between a nurse and a patient (Harding et al., 2006). The tenets of the humanistic nursing theory were applied in this study where the nurse focused on the unique needs of each patient and addressed the physical and psychosocial needs of the child.

Nature of the Study

In this study, I used a quantitative approach and cross-sectional design. I conducted a chart review of children who received palliative care integrated with standard HIV care over a 3 month period. Lowther et al. (2012) collected data over a similar period to show the effect on treatment outcomes in adults. Treatment outcomes, including the psychosocial health and physical health of these children, were compared to those who received standard HIV care and treatment. Data were collected from a nongovernmental hospital providing HIV care and treatment to adults and children. The hospital provides palliative care that is optional for children. Those who do not wish to enroll for palliative care may opt out and continue to receive standard care. Data from children who received palliative care were compared to those who did not opt to receive palliative care as part of standard care. Children aged between 5 and 15 years and who had been on antiretroviral therapy for at least 3 months were eligible to be enrolled in the study. A quantitative empirical study enabled me to collect empirical evidence of the impact of integrating palliative care into standard HIV care, and the results may fill the current gap in the literature.

Definition of Terms

HIV-positive: A child will be considered HIV-positive based on a positive DNA PCR result (Ministry of Health, 2014).

Standard HIV care: Care and treatment offered to HIV-positive children based on guidelines issued by the Ministry of Health in Kenya. Standard HIV care includes a monthly visit to the clinic. During such visits, the child is seen by the triage nurse first and then the doctor. A child on antiretroviral therapy may present with physical symptoms that are addressed. The doctor would also write a fresh prescription of the drugs necessary for treatment (Ministry of Health, 2014). Children, whose adherence levels are low, determined by the pill count, are sent for special adherence counseling by a trained counselor (Ministry of Health, 2014). Children with opportunistic infections and those with side effects of antiretroviral therapy are provided medication for such conditions (Ministry of Health, 2014).

Palliative care: Care that involves discussion with the patient on pain and quality of life-related issues. It may also include additional clinic visits. Palliative care is integrated with standard care offered to HIV-positive children at the clinic. Such care lays emphasis on holistic patient-centered care, including the impact of illness on the family and recognition of the importance and interdependence of physical, psychosocial, social, and spiritual symptoms, alongside antiretroviral therapy (WHO, 2006).

Assumptions

An important assumption I made in this study was that what palliative care entails had been explained to all pediatric patients and parents in the hospital. The choice of opting out of this service was assumed to be of the parents and the child and not of the health care provider. Lowther et al. (2012) had used a 3 month period to evaluate treatment outcomes in adults on antiretroviral therapy. Another assumption was that a similar period could be used to assess the impact of integration in children. The pediatric quality of life (PEDSQL) inventory has been validated for use in children in some age groups (Ewing, King, & Smith, 2009; Ferreira et al., 2014). It was also assumed that the tool would be applicable in an outpatient HIV clinic in sub-Saharan Africa. It was further assumed that palliative care is offered uniformly to all children with HIV in the hospital.

Scope of the Study

I conducted the study in a single outpatient HIV center in Kenya providing care and treatment services to HIV-positive children. The study did not involve collecting data directly from participants. All pediatric patients aged between 5 and 15 years on antiretroviral therapy were eligible for the study and enrolled as participants. This age group was selected from studies in which the use of the PEDSQL has been validated (Ewing et al., 2009; Ferreira et al., 2014). Children registered for HIV care and treatment at this facility are Kenyans. There was no majority ethnic group amongst the children who accessed care at the center at the time of the study. HIV-positive children are followed from diagnosis to 15 years of age in this center. After this age, they are transferred to the adult clinic.

Limitations

The first limitation was that I conducted this study in a general outpatient setting in a single center in Kenya offering comprehensive HIV-positive care. Chart reviews were conducted on the pediatric population at the outpatient HIV center. I conducted quantitative analysis on data obtained from the files and not first hand from patients. Reliable conclusions can only be drawn if the data obtained were accurate. Another limitation was that the PEDSQL inventory (Lyon et al., 2014) was used in the hospital to collect information on pain and physical symptoms. This inventory is based on patient reporting and thus remains open to information bias.

Psychosocial functioning was assessed by retrieving information on social functioning, emotional functioning, and school functioning. HIV-related stigma is common in children and particularly in school children (Lin et al., 2010; Surkan et al., 2010). It is possible that school functioning was affected by the stigma HIV-positive children face in schools.

Information on socioeconomic status is important in the field of HIV, especially because of the inequalities in HIV prevalence in sub-Saharan African countries (Hajizadeh, Sia, Heymann, & Nandi, 2014). However, information on socio-economic status is not routinely collected and recorded in patients' charts in the HIV clinics due to the sensitivity of the information and the likelihood of getting inaccurate information. This was also a potential limitation in this study.

While cross-sectional studies are easier to conduct than other study designs, the studies have limitations when it comes to establishing causal relationships and directionality (Frankfort-Nachmias & Nachmias, 2008). Hence, researchers use this design to describe the pattern of relationship between variables (Frankfort-Nachmias & Nachmias, 2008). The components of manipulation and control that are present in true experimental studies are lacking in a cross-sectional study design (Frankfort-Nachmias & Nachmias, 2008).

Significance

The results of this study may fill a gap in understanding the impact of integrating palliative care into standard HIV care provided to children on antiretroviral therapy. Despite antiretroviral initiation, people living with HIV/AIDS continue to suffer the symptoms of burden of pain and psychosocial and mental stress affecting their general well-being and adherence to antiretroviral treatment (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). In fact, people living with HIV/AIDS have a higher burden of physical problems compared to the general population (Harding et al., 2014; Harding & Sherr, 2014; Parker et al., 2014). The few studies conducted to show the effect of integrating palliative care into standard HIV care have shown promising results on treatment outcomes in adults (Green et al., 2010; Lowther et al., 2012). However, these studies did not include children. HIV-positive children in sub-Saharan Africa present with additional burden and thus empirical evidence is required to assess the impact of palliative care on their health status (Connor et al., 2014). This study will address this gap and provide evidence on the impact of palliative care on health status in HIV-positive children.

Providing evidence-based and effective care alongside antiretroviral therapy in children may improve treatment outcomes in children who are HIV-positive. Application of an integrated approach may lead to the provision of holistic care to HIV-positive children. Such care may be provided to any child who is HIV positive regardless of the stage of the disease. A further impact the approach may create is on treatment outcomes in children. This could then have an impact on the children's longevity and lead to better mental and physical health. Therefore, insights from this study could be applied in any HIV care and treatment center for children and contribute to the Walden mission of bringing about positive social change.

Summary

Palliative care lays emphasis on holistic, patient-centered care, including the impact of illness on the family and recognition of the importance and interdependence of physical, psychological, social, and spiritual symptoms, alongside antiretroviral therapy (WHO, 2006). Needs assessments of palliative care have been carried out in Zimbabwe, South Africa, Uganda, and Kenya (Connor et al., 2014). Such needs include physical, social, psychological, and spiritual care (Nakawesi, et al., 2015).

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on health outcomes in HIV-positive children on antiretroviral therapy. I conducted this study in Mombasa, Kenya, which is a low-income setting (WHO, 2014). I used a cross-sectional study using a quantitative mode to answer specific RQs and assess the outcome of integrating palliative care into outpatient HIV care provided to HIV-positive children.

The philosophical perspectives of the humanistic nursing theory apply to the practice of palliative care that also focuses on holistic care, open discussions between the nurse and the patient, and emphasizing the unique relationship between a nurse and a patient (Harding et al., 2006). I used the PEDSQL, which has been validated in some studies, to assess the quality of life outcomes in children receiving palliative care. Limitations of the study revolved around the use of a cross-sectional study design in which causal relationships and directionality are difficult to determine (Frankfort-Nachmias & Nachmias, 2008). This research may fill a gap in understanding the impact of integrating palliative care into standard HIV care provided to children on antiretroviral therapy. Chapter 2 will include a restatement of the problem and the purpose of the study, a concise synopsis of the current literature, and a detailed literature review on the subject and the theoretical and conceptual framework.

Chapter 2: Literature Review

Introduction

Despite antiretroviral initiation, people living with HIV and AIDS continue to suffer the symptom burden (Campos et al., 2009; Fan et al., Chen, 2011; Harding et al., 2006; Willard et al., 2009). The intensity of physical problems is higher in the HIV-positive population compared with the HIV-negative population (Harding & Sherr, 2014; Parker et al., 2014). HIV-positive patients also have a higher prevalence of anxiety and depression compared with the general populations as well individuals with other chronic conditions such as renal failures or cancers (Lowther et al., 2014). This compromises the quality of life of HIV-positive patients (Braithwaite et al., 2008).

Palliative care lays emphasis on holistic patient-centered care including the impact of illness on the family, and recognition of the importance and interdependence of physical, psychological, social, and spiritual symptoms alongside antiretroviral therapy (WHO, 2006). Integrating palliative care could have positive pain reduction outcomes in people living with HIV/AIDS (Green et al., 2010).

Lowther et al. (2012) used a mixed methods approach to show the impact of palliative care on treatment outcomes in Kenya and South Africa. While these isolated studies have been conducted on adult patients, there is little or no evidence to demonstrate treatment outcomes for children receiving palliative care alongside antiretroviral therapy (Harding et al., 2014).

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The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. I conducted the study in Mombasa, Kenya which a low-income country (WHO, 2006). I used a quantitative research mode and conducted chart reviews to obtain the required information.

This chapter will include a description of the epidemiology of HIV/AIDS in sub-Saharan Africa. I will also include a description of palliative care in the context of HIV/AIDS, a synopsis of the humanistic nursing theory, and an in-depth review of the available literature on palliative care models in children. A review of literature that describes treatment outcomes will also be included.

Literature Search Strategy

I conducted my search literature in three electronic databases: MEDLINE, CINAHL, and PsychInfo. The keyword search terms I used included: *pediatrics, minors, infant, child, palliative care, hospice care, end of life care,* and *HIV/AIDS.*

To extend my search, I also searched for and obtained individual articles from the reference lists of articles obtained from the three databases. My review was not limited to studies that took place in sub-Saharan Africa but instead included articles on palliative care worldwide. Because of the paucity of information available, the search was extended to include articles from 1990 to the present. I also conducted a separate search for literature on the PEDSQL inventory using the same databases. Similarly, an independent search was conducted to obtain available literature on the humanistic nursing theory. I classified the information obtained into eight broad categories: (a) need for additional care for HIV-positive children, (b) essential medication, (c) factors related to the provision of palliative care, (d) perception of terminal illness in children, (e) treatment outcomes, (f) spirituality, (g) use of validated tools in children and adolescents, and (h) the PEDSQL.

Theoretical Foundation

According to the WHO (2005), there is a need for expert end of life and palliative care for patients with fatal chronic diseases. Death is a universal phenomenon. The philosophy of palliative care is aimed to affirm life and considers death as a normal process in the life cycle (Wu & Volker, 2011).

The focus of palliative care is to provide comfort and compassionate care for patients whose life-limiting illness may or may not respond to pharmacotherapy (Wu & Volker, 2011). Using the philosophy of palliative care, the health care provider can focus on the unique needs of each patient and address the physical, social, psychological, cultural, social, and spiritual needs of the patient (Wu & Volker, 2011). Nurses play an integral role in the provision of palliative care and are in the best position to provide direct care on a continual basis (Wu & Volker, 2011). The humanistic theory of nursing was developed by Patterson and Zdedard in the early 1960s (McCamant, 2006). In the next two decades, the theory continued to be developed further and was then categorized as a meta-theory (Wu & Volker, 2011).

Franca et al. (2013) used the humanistic theory of nursing as a basis to conduct a study to determine communication in palliative care contexts from nurses' perspectives. The researchers conducted a field study using a qualitative approach (Franca et al., 2013). The authors aimed to determine the importance of communication in palliative care for children with terminal cancers. The researchers established two emerging themes from the empirical study: strategies to humanize nursing and strategies to reinforce ties between the nurse and the child (Franca et al., 2013).

Amongst the tenets of the humanistic nursing theory is the building of trust in the involvement of care provided from one human being to another (Franca et al., 2013). The theory further lays emphasis on the unique meaning of the human being and the processes of human interaction (Franca et al., 2013). Proponents of the humanistic nursing theory use it to emphasize the live experience of nurses (Kleiman, 2009; McCamant, 2006; O'Connor, 1993). In other words, it is the phenomenon of nursing as experienced in the everyday world (Paterson & Zdedard, 1976). In this theory, the process of nursing is described in abstract terms in which the nurse and the patient meet in a goal-oriented direction to improve well-being in the lived world (McCamant, 2006; Paterson & Zdedard, 1976). Because it is a meta-theory, the humanistic nursing theory can be considered a general theory that may give rise to other specific theories in nursing (Wu & Volker, 2011).

The theory applies to palliative care because the focus of palliative care is to provide comfort and compassionate care for patients (Wu & Volker, 2011). Nurses play an integral role in the provision of palliative care to children with chronic terminal illnesses. Such provision of care involves intersubjective interaction between the nurse and the child that is the core emphasis of the humanistic nursing theory (Paterson & Zdedard, 1976).

The philosophical perspectives of the humanistic nursing theory are relevant to the practice and provision of palliative and hospice care provided to terminally ill patients (Wu & Volker, 2011). Paterson and Zdedard (1976) used the theory to describe each human being as an individual with unique needs in a present situation. Each individual thus has a view by which they hear, see, and perceive the world (Wu & Volker, 2011). Through such views, individuals have the potential to experience their authentic self and undergo authenticity-experiencing (Wu & Volker, 2011). The individuals thus become aware of themselves in the world and are in a position to establish and share relationships with others (Wu & Volker, 2011). Palliative care recognizes the unique needs of each patient as an individual. The individual is recognized as one with unique needs and a unique world-view which can then be shared with nurses (McCamant, 2006).

The humanistic nursing theory describes a human being as an individual who has the inherent capacity and freedom to choose how to respond to a particular situation (Wu & Volker, 2011). Such reflection is important as it allows the human being to reflect on their past experiences and better understand themselves in the present situation (Wu & Volker, 2011). On its part, palliative care allows the nurse and the patient to use such past reflections to understand better the meaning of the end of life (Wu & Volker, 2011).

O’Connor (1993) provided the relevance of the humanistic nursing theory in palliative care by describing the patient as the one being nursed (person as patient) and the nurse as the person nursing (person as a nurse). Such interaction is the basis of palliative care (Wu & Volker, 2011). The nurse and the patient are two unique individuals with their worldviews and who meet for a common goal – well-being of the patient (Wu & Volker, 2011). Such interaction had earlier been described by Peplau in 1952 (McCamant, 2006). The goal of palliative care is to improve the physical, psychosocial, emotional, and spiritual well-being of the patient (Harding et al., 2014).

While palliative care depicts a glove and hand fit in the humanistic nursing theory, some limitations should be noted in the practical application of the humanistic theory. Basic concepts of the theory, similar to the ones postulated by Peplau in 1952, include humanism, existentialism, and phenomenology (Paterson & Zdedard, 1976). A second limitation is an emphasis on the intersubjective nature of the relationship between the patient and the nurse. Such a relationship includes the awareness and choice to respond to a particular situation (McCamant, 2006). The application becomes difficult in the case of children and individuals who are not competent to make free and responsible choices for themselves in a particular situation (Wu & Volker, 2011). Finally, building a strong relationship between the patient and the nurse, as described in the humanistic nursing theory, takes time (Wu & Volker, 2011). Most clinical encounters between the patient and the nurse are brief, and it may take a long time to establish this relationship in a clinical setting.

Despite the limitations, the tenets of palliative care and those of the humanistic nursing theory seem to match, and the humanistic nursing theory can be applied to palliative care provision to preserve the child’s physical, social, moral, and spiritual integrity (Franca et al., 2013). I designed this study using the constructs of the humanistic nursing theory which are applicable to the provision of palliative care.

Literature Review

HIV/AIDS in Sub-Saharan Africa

HIV belongs to a group of virus called retroviruses (Centers for Disease Control and Prevention [CDC], 2015). The virus was identified in humans in 1984 although it is now known that the virus was in existence long before it was identified (Hay et al., 2014). The virus infects the lymphocytes, monocytes, and macrophages weakening the immune system (Hay et al., 2014). The virus binds to the CD4 receptor protein and the chemokine receptor found on the surface of target cells (Hay et al., 2014). As the number of infected CD4 cells gets higher, the humoral and cell-mediated immunity are affected (Hay et al., 2014). Progression of the infection results in AIDS (Hay et al., 2014).

Transmission of HIV is through sexual contact with an infected individual, percutaneous exposure to contaminated blood, or vertical transmission from an HIV-positive mother to the infant (Hay et al., 2014). Vertical transmission of HIV may occur either in utero, during delivery, or as a result of breastfeeding (CDC, 2015). Diagnosis of HIV is made by testing for the presence of antibodies in blood (Hay et al., 2014). A child below 18 months of age can be tested using DNA-PCR while a child above 18 months of age can be tested using Enzyme Linked Immunosorbent Assay (Ministry of Health, 2014). Clinical diagnosis of AIDS is made when an HIV-infected child develops an opportunistic infection or certain malignancies (Hay et al., 2014; Ministry of Health, 2014).

HIV is a major contributor to morbidity and mortality in children, moreso in sub-Saharan Africa (Connor et al., 2014). Of the 33 million individuals living with HIV/AIDS worldwide, two-thirds are in sub-Saharan Africa (CDC, 2015). The number of children living with the virus worldwide is 3.3 million (Avert, 2014). Greater than 90% of the children infected with the virus are in sub-Saharan Africa (Harding et al., 2014).

Kenya is located on the east coast, south of the Sahara in Africa, and so, it is a sub-Saharan African country. The area of the country is 219 square kilometers with a population of slightly above 44 million (Kenya National Bureau of Statistics, 2014). Forty-four percent of the population is employed either full-time or on a part-time basis, while the rest are either unemployed or retired (Kenya Mpya, 2012). The poverty rate in Kenya is 37.6% (Kenya Mpya, 2012). The country is classified as a developing country (Kenya Mpya, 2012). Life expectancy at birth is 69 years (Kenya Mpya, 2012). Maternal mortality is 360 per 1,000 live births (Kenya Mpya, 2012). The under-5 mortality rate is 85/1000 live births and the gross domestic per capita income (GDP) is 819 (The World Bank, 2014). Twenty-six percent of the population lies between 6 and 19 years of age (Kenya Mpya, 2012).

In Kenya, HIV prevalence was at its peak in 1995–1996 at about 10.5% (National AIDS Control Council [NACC], 2014). By 2003, the peak had declined by almost 40% to 6.7% (NACC, 2014). Since then, HIV prevalence in the general population in Kenya has been relatively stable ranging from 5.6–6.7% (NACC, 2014). One reason for the decline in the last decade is the availability of antiretroviral drugs in the country (NACC). In

2012, there were 1.6 million people living with HIV/AIDS in the country (United Nations Program for HIV/AIDS [UNAIDS], 2014).

The rates in children are different from adults. Worldwide, 10,000 children acquire HIV infection daily (Mothi et al., 2011). In 2011, 2.5 million children were reported to have been infected with HIV perinatally (UNAIDS, 2012). The rate of mother to child transmission is less than 2% in developed countries and is as high as 40% in some developing countries (Khobondo, Gacheru, & Khamadi, 2015). In Kenya, 12,984 children in 2012 and 12,940 children in 2013 acquired the infection (Kenya AIDS Indicator Survey [KAIS], 2014). In 2012, there were 200,000 children living with HIV/AIDS in the country (UNAIDS, 2014). In 2013, 10,390 children less than 1 year of age died in Kenya due to HIV infection (KAIS, 2014). Total number of deaths in Kenya in the same year were 57,000 (UNAIDS, 2014).

The guidelines in Kenya require initiation of antiretroviral therapy in all HIV-infected children below 10 years of age regardless of the WHO stage of the disease or the CD4 count (Ministry of Health, 2014). In children above 10 years of age, antiretroviral therapy is initiated when the CD4 cell count is less than or equal to 500 cells/mm^3 regardless of the WHO stage (Ministry of Health, 2014). HIV-infected children in Stage 3 or 4 of the disease, or those with hepatitis B virus or tuberculosis are initiated on antiretroviral therapy regardless of the CD4 count (Ministry of Health, 2014). Children born to HIV-positive mothers in whom the DNA-PCR testing cannot be conducted before 18 months of age should be initiated on presumptive treatment (Ministry of Health, 2014).

HIV is the leading cause of mortality in Kenya (Ministry of Health, 2014). Twenty nine percent of all deaths in the country are due to HIV (Government of Kenya, 2014). The Government of Kenya, through the Ministry of Health, developed HIV care and treatment guidelines for the provision of antiretroviral therapy to HIV-infected individuals (Ministry of Health, 2014). Kenya has partnered with the USA in the roll out of antiretroviral therapy in the country. The United States initiated the PEPFAR in 2003. The initial grant was $15 billion for all countries (Harding et al., 2014). Funding has increased by more than three times in the next phase of PEPFAR (CDC, 2015). An evaluation of PEPFAR indicated that goals for initiating individuals on anti-retroviral therapy are being met (CDC, 2015). However, an assessment of overall operational and implementation of comprehensive programs that include palliative care is yet to be conducted (Harding et al., 2014).

Provision of antiretroviral therapy has expanded in the last decade in sub-Saharan Africa (Ben-Farhat et al., 2013). The Government of Kenya has developed the HIV care policy which requires comprehensive care to be offered to all individuals living with the virus. Comprehensive care includes food by prescription of malnourished as well as access to pain medication (NACC, 2012). However, a study conducted in 60 pharmacies in the country indicated that strong pain killers are rarely available for people living with HIV/AIDS (Harding et al., 2010).

Palliative Care

According to WHO palliative care is an approach that can be adopted to improve the quality of life of patients facing terminal illnesses (WHO, 2005). The approach is not limited to the patient but also extends to families. It is aimed to prevent and curb the suffering of such patients by identifying and addressing their physical, social, and spiritual needs (Cameron & Johnston, 2015). Palliative care is aimed at assessing the needs of the patient and hence plan, implement, and evaluate interventions directed towards satisfying such needs (Cameron & Johnston, 2015).

People living with HIV/AIDS experience a wide array of symptoms such as pain, cough, shortness of breath, fatigue, diarrhea, fever, nausea, and confusion (WHO, 2005). Hence, they would need additional care compared to patients without HIV/AIDS. The purpose of providing palliative care to such patients would be to relieve the suffering of such individuals who have to cope with the adverse effects of antiretroviral therapy (WHO, 2005). Palliative care is also intended to allow the individual infected with the virus to lead a normal life and continue with daily life activities and reduce the burden on health care resources (WHO, 2005).

Palliative care is not a new concept in HIV care and treatment. Prior to the widespread access to antiretroviral therapy, palliative care was the standard of care offered to individuals diagnosed with HIV (Selwyn & Rivard, 2003). UNAIDS had advocated the provision of palliative care as part of best practices in 2010 (UNAIDS, 2010). In sub-Saharan Africa, palliative care was provided by community health nurses (Wube, Horne, & Stuer, 2010). It is interesting to note that despite being defined almost 15 years ago, there are few models of care that have been reported in the literature (Harding et al., 2014).

Henley (2002) conducted a hospital care study in South Africa. The author conducted a retrospective chart review of children who died of HIV in a hospital. Only 44% of the patients had a comfort care plan, while 55% of the patients had documented pain and distress in the last 48 hours (Henley, 2002). The comfort care plans documented were incoherent, and many included interventions unlikely to benefit the patient (Henley, 2002). Despite the results, the model presented in this study focuses on hospital care offered to HIV-positive children. With a large number of HIV-positive children being admitted, providing palliative care within the hospital may be a feasible option (Harding et al., 2014). Limitations of this model include ensuring availability of trained staff within the in-patient department. Secondly, palliative care provision would be limited to hospitalized patients only.

Uys (2003) described a model of home-based care that linked hospitals, clinics, and care given at home in a continuum. The model was developed in a rural hospice in South Africa (Uys, 2003). The idea was to provide a continuum of care from diagnosis to death for people living with HIV/AIDS (Uys, 2003). The model comprised of counseling and supporting patients who were relatively symptom free with an emphasis on palliative care (Uys, 2003). The model was developed in a background of a developing country where arguably all patients diagnosed with HIV qualify for palliative care (Uys, 2003). A collaboration of hospice, hospital, and primary health care clinics is the basic tenet of this model (Uys, 2003). An effective referral network is required for this model to succeed (Harding et al., 2014).

Knapp et al. (2009) described a similar model developed in South Africa in 1998. The model comprised of clinical services, palliative day care services, counseling, and speech therapy (Knapp et al., 2009). The model also included bereavement support, counseling, and child care training for family members (Knapp et al., 2009). The services were provided from homes, day care centers, and hospices (Knapp et al., 2009).

A novel model was proposed by Harding, Brits, and Penfold (2009). The model was tested in South Africa. In this model, the hospice initiated antiretroviral therapy for HIV-positive children who were eligible under the WHO guidelines (Harding et al., 2009). In South Africa, children would die before accessing antiretroviral therapy in the HIV clinics (Harding et al., 2009). This would be because of poor nutrition, respiratory illnesses, neurological illnesses, and poor care provision (Harding et al., 2009). The model, which was based within an existing hospice, included providing medication, nursing, dietician services, physiotherapy, and occupational therapy to children (Harding et al., 2009). Thirty seven children were initiated on antiretroviral therapy and of these, 31 were alive at the end of 6 months. There was an average increase in weight of 3.2 kilograms, and CD4 counts were more than double from baseline with a mean increase of 467 cells/mm^3. Twenty three children had undetectable viral load at the end of the study (Harding et al., 2009). There has been no model tested from an outpatient setting where palliative care is integrated with outpatient HIV care and treatment.

Palliative care is required even after the initiation of antiretroviral therapy (Merlin et al., 2012). However, in Kenya supportive care is not widely accessible for people living with HIV/AIDS (Cramp & Bennett, 2013). Some level of care may be provided informally by the family members (U.K. Consortium on AIDS and International Development, 2013). However, the stigma and discrimination associated with HIV/AIDS and the requirement of support for the family as well hinder the provision of such care (Powell & Hunt, 2013).

Aspects of palliative care provision have been reported in adults for conditions other than HIV. Symptom management in patients with asthma and chronic obstructive pulmonary disease (COPD) associated with a decrease in depression have been reported (Kotses et al., 1995; ZuWallack, Meek, & Jain, 2011). There is no evidence of an effective model for symptom management in HIV care. However, the literature review revealed unaddressed physical symptoms in HIV-positive patients (Farrant et al., 2012; Harding et al., 2010; Harding et al., 2012, Merlin et al., 2012; Perry et al., 2013).

Psychological, social, and spiritual patient and family support have shown benefits in patients with breast cancer (Ali et al., 2003; Fogarty et al., 1999; Montezari et al., 2008). Such psychological and social support has been provided in some countries for HIV-positive patients and has been documented (Mo & Coulson, 2013; Petersen et al., 2014; Rounds, Galinsky, & Despard, 1995; Wube et al., 2010). Patient education has shown benefits in patients with stroke, cancer, and diabetes (Bakitas et al., 2009; Brown, 1992; Forster et al., 2012; Miller et al., 2005). Patient education in HIV has also shown benefits (Miles et al., 2003; Pomeroy et al., 1997; Sengupta et al., 2011). All studies reporting aspects of palliative care, in HIV and non-HIV patients were conducted on adults. There has been no reported study for such aspects of palliative care in children.

Palliative care proper or comprehensive palliative care which includes all aspects combined has shown improvements in patients with heart failure, cancer, and COPD (Higginson & Evans, 2010; Rabow et al., 2004; Temel et al., 2010). Evidence of the benefits of palliative care has been reported in few studies in adults (Green et al., 2010; Harding et al., 2010, Harding et al., 2013; Lowther et al., 2014).

Need for Additional Care for HIV-Positive Children

In some sub-Saharan African countries, children have additional responsibilities compared to children living in the developed world (Connor et al., 2014). Children in sub-Saharan Africa have to care for their sick parents or grandparents. In some instances, they even have to take up financial responsibilities for the entire family (Connor et al., 2014). This is mostly in cases where parents are in advanced stages of the HIV infection. Such children are brought up by grandparents who themselves demand care justified by their age and physical health (Connor et al., 2014). Children of HIV-positive patients further have to cope with the deaths of their parents. There is thus increased psychosocial stress on such children (Connor et al., 2014).

HIV-positive children suffer from physical symptoms such as fatigue, changes in cardiovascular, respiratory, neuromuscular, and mental symptoms (CDC, 2015). Some of the symptoms continue to remain even after the start of antiretroviral therapy (Harding et al., 2014). Once antiretroviral therapy is initiated, there is the risk of immune reconstitution syndrome. This further increases the symptom burden faced by the children. Such physical symptoms need to be addressed.

A study in South Africa revealed significant findings in hospitalized HIV-positive children. HIV-positive children presented with discomfort, pain, and distress (Ritcher et al., 2009). Such symptoms were associated with stressful social circumstances, stigma due to HIV, compromising economic environment, overburdened health care institutions, and lack of adequately trained staff in the hospitals (Ritcher et al., 2009). Additional needs identified for such children include addressing their cognitive, motor, and social development (Ritcher et al., 2009).

Poor adherence to antiretroviral therapy is an additional problem in sub-Saharan Africa (Loefler, 2002). This limits the virologic and immunologic response to drug therapy. High morbidity in sub-Saharan African can partly be explained by this (Harding et al., 2014). In settings where adherence is not a concern, antiretroviral therapy has been associated with longevity. In turn, this has created an even higher demand for palliative care that is required to address the management of pain and symptoms associated with adverse effects of drug therapy (Harding et al., 2014). Connor et al. (2014) acknowledged the fact that despite the rapid scale-up of HIV treatment in both adults and children, provision of palliative care services has not expanded at an equal pace.

Needs assessments have been conducted in some countries in sub-Saharan Africa. These include Zimbabwe, Uganda, Kenya, and South Africa (Connor et al., 2014; Nakawesi et al., 2015). Despite such assessment, the magnitude of the need has not been addressed (Connor et al., 2014). Harding et al. (2010) conducted an appraisal to identify best practices in palliative care for children. The authors concluded that compared to adults, there had been little progress in pediatric palliative care despite the need (Harding et al., 2010). Connor et al. (2014) presented similar findings in their comment on the number of reported care models in pediatric palliative care.

Nakawesi et al. (2015) reported specific palliative care needs of HIV-positive children in Uganda. HIV-positive children require physical, social, psychological, and spiritual care. Such needs may be similar to those demanded by children with terminal cancers (Nakawesi et al., 2015). Nevertheless, it is important to note that HIV-positive children face additional challenges compared to those with cancers (Connor et al., 2015; Harding et al., 2010; Ritcher et al., 2009). Bomba et al. (2010) conducted a study on HIV-positive children in Italy and found out that while antiretroviral therapy has improved longevity in children, factors such as disease morbidity, familial, and environmental conditions continue to negatively affect the children's quality of life. Harding et al. (2014) propose a multidisciplinary approach to address such needs.

An advantage of integrating palliative care into standard HIV care for children would be a reduction in the burden of care on nurses (Ritcher et al., 2009). A more compassionate approach to addressing the child's distress can thus be used. Wu and Volker (2011) described the application of the humanistic theory in palliative care which can result in building partnerships between the nurses and the caregivers. Additional gaps in the provision of HIV care and treatment to children in sub-Saharan Africa include psychosocial caregiver support, child psychosocial support, and pain management (Ritcher et al., 2009).

Lack of discussion on palliative care and end of life care with parents creates a sense of anxiety, isolation, and fear amongst HIV-positive and adolescents (Wiener et al., 2012). Children and adolescents who have information on palliative care and end of life seem to take an interest in the management of their illness (Wiener et al., 2012). Such discussions with parents and children may have an additional advantage of addressing myths, false beliefs, and unrealistic expectations (Wiener et al., 2012).

One major limitation of the studies that have conducted a needs assessment of palliative care in HIV-positive children is the use of morbidity and mortality data on children (Connor et al., 2014). This limits the definition of palliative care to end of life instead of from the time of diagnosis when it should ideally begin (Connor et al., 2014). The South African study used prevalence data instead of mortality data to assess the need for palliative care (Connor et al., 2014). However, in this study, secondary data was used instead of primary data which then creates room for an over or underestimation.

Essential Medication

Comprehensive management of HIV requires an effective supply chain management. Common drugs used to manage opportunistic infections and pain have to be available in antiretroviral pharmacies to address the needs of children (Harding et al., 2014). One limitation in comprehensive care provision in sub-Saharan Africa is a lack of a constant supply of drugs. The supply of ARV has been fairly constant in sub-Saharan Africa. However, drugs used in the management of opportunistic infections such cotrimoxazole and isoniazid are frequently out of stock (Harding et al., 2014). Drugs used for pain management are also limited in supply in many centers (Harding et al., 2014). Lack of essential medication for pain management for HIV-positive children in Africa is associated with poor economic conditions, lack of trained staff to prescribe such medications, lack of constant supply of medication, and strict regulations for prescribers (Harding et al., 2014). A three step pain management ladder was identified by WHO mainly for the management of pain in cancer patients (WHO, 2015). Recommendation from WHO is that pain management in a patient can be conducted using a three step ladder approach. Oral administration of pain killers should be in the following order: non-opioids, and then mild opioids, and then as appropriate, strong opioids (WHO, 2015).

A cross-sectional study was conducted in randomly selected pharmacies in Kenya and Uganda by Harding et al. (2014). Sixty pharmacies were randomly selected in each country. The data collection tool was piloted in a large and a small pharmacy. Information was collected on type of facility, type of pain management drugs available, minimum stock levels, the number of stock out situations (Harding et al., 2014). Amongst the analgesics, nonopioid drugs were the most commonly available ones but only in large pharmacies. Strong opioids such morphine were available only in 7% of the pharmacies. None of the facilities had minimum stock levels. The study reveals a weak system of pain management in the two countries. Availability of common pain management drugs would be the first step in managing pain. Findings of this study were from two countries. However, a similar situation may exist in other countries with similar backgrounds. Pain management is an essential component of palliative and absence of painkillers may limit the scope of comprehensive palliative care offered to children with HIV.

Related Factors

Lindley et al. (2014) report findings from a retrospective longitudinal study in which they collected data over a 7 year period. The study revealed that small and medium-sized health centers do not provide pediatric palliative care services. An exception was those health centers that were affiliated with professional groups that provide palliative care services to children (Lindley et al., 2014). Membership or affiliation with professional bodies requires maintaining a minimum standard of service to be provided. Such standards would include palliative care as part of the comprehensive package of care accorded to children living with HIV.

Other factors identified in the literature associated with lack of provision of palliative care include inadequate training of health care providers (Lyon et al., 2008). In settings where the health care providers are not trained, they are not comfortable in discussing end of life and hospice care. Health care providers not trained in the provision of palliative care fear that such conversation may increase anxiety and fear in the children and their families (Lyon et al., 2008). Such health care providers themselves show a need for counseling to counter their emotions when handling a dying patient (Lyon et al., 2008). The belief that discussing end of life with children and young adults is a difficult process was negated in the study by Wiener et al. (2012) who demonstrated that children and young adults who are aware of their health status are, in fact, more interested in discussing their management with health care providers. Nevertheless, developmentally appropriate language and approach has to be used to address end of life in children. Training health care providers in palliative care provision may provide a solution to this barrier. Such training may also clear misconceptions that exist amongst health care providers.

Amery et al. (2012) provide additional insights of the factors associated with the provision of palliative care for children. There is a general acknowledgment of the importance of palliative care in sub-Saharan Africa (Amery et al., 2012). However, the doctors do not provide such care, and they attribute it to lack of confidence in handling the issue of end of life (Amery et al., 2012). The task of providing palliative care, particularly in children, has been described as intimidating and difficult especially for doctors and other health care providers who have not been trained in this field (Amery et al., 2012). HIV out-patient government clinics in sub-Saharan Africa are characterized by a large number of patients and low salary scales for health care providers (Amery et al., 2012). This, in turn, leads to low working morale and fatigue amongst clinical staff.

Doctors from Asia-Pacific, on the other hand, talk of lack of expertise in palliative care provision (Amery et al., 2012). They prefer doctors from abroad to visit their clinics and provide palliative care to children (Amery et al., 2012). Such findings are similar to those noted by Lyon et al. (2008). Lack of expertise and low levels of confidence is a deterring factor for health care providers. While doctors from Asia prefer trained health care providers to provide palliative care training, such visits are not frequent. Health ministries in such countries further provide minimum to almost no support for palliative care provision to HIV-positive children (Amery et al., 2012). However, health care providers and even non-health care providers in the study showed interest in palliative care.

Further insight into factors associated with the provision of palliative care is provided by Connor and Uddin (2015). Not all outpatient centers provide palliative care services. However, some have a higher referral rate to a pediatric palliative care unit compared to others (Connor & Uddin, 2015). The study conducted in Florida revealed that while greater than half the nurses working in the HIV clinic would refer children to a pediatric palliative care unit, the tendency was higher amongst non-ICU nurses compared to ICU nurses (Connor & Uddin, 2015). Other factors associated with referral to the specialized units include maturity and level of experience of the attending nurse. More experienced nurses tend to demonstrate a high level of comfort provision compared to less experienced nurses. Hence, more experienced nurses would retain the patient instead of referring them to a pediatric palliative care unit (Connor & Uddin, 2015).

Perception of Terminal Illness in Children

Death and terminal illness are perceived differently in different cultures. There is limited literature on the contextual meaning of terminal illness in children (Connor et al., 2014). This could further explain why there is a limited body of literature on palliative care in children. Models of care can only be successfully implemented if the meaning of terminal illness in children, its psychosocial impact on the child and the family and its impact on the well-being of the child is understood (Connor et al., 2014).

Lyon et al. (2008) reported fear of doctors and health care providers to discuss palliative and hospice care with children. There is a general belief that such discussions may lead to anxiety and even depression amongst the patients and the family members (Lyon et al., 2008). It is also feared that health care providers may themselves require additional counseling when handling a dying child (Lyon et al., 2008). The belief was contradicted in a later study by Wiener et al. (2012). This study was a first of its kind in that it allowed adolescents and young adults to discuss their end of life care. The study revealed that children and young adults are, in fact, open to such discussion, and they take it with much interest (Wiener et al., 2012). It was not surprising to note that less than half the children had ever discussed end of life with their parents (Wiener et al., 2012). Lyon et al. had earlier reported the difficulty and hesitance that parents have when discussing end of life with children.

The 2008 study by Wiener et al. had reported the use of a document such as five wishes. Such a document may be used to open up discussions on end of life between parents and young children. However, it can only be applied to children who are old enough to express themselves. The tool may be of limited use in very young children who cannot express themselves (Wiener et al., 2008). Nevertheless, its use in older children may be useful for parents and caregivers to understand the perception and the contextualized meaning of terminal illness in children (Wiener et al., 2012).

Understanding terminal illness also includes understanding the special needs of terminally ill patients, particularly the motor, socio-emotional, and the cognitive development needs of children (Ritcher et al., 2009). Amery et al. (2012) report the relative confidence of doctors and nurses in the provision of palliative care. Nurses seem to be in a better position than doctors to understand the special needs of such children (Amery et al., 2012). Nurses understand the family dynamics, level of family support, end of life care, psychosocial problems, holistic assessment, spirituality, play and development, and bereavement better than doctors (Amery et al., 2012). On their part, doctors showed a higher level of confidence in pain management and end of life care

(Amery et al., 2012). However, it is important to note that this was a global study allowing doctors and nurses from all over the world to response to an online questionnaire. The responses indicated that doctors and nurses from Africa were less confident than doctors and nurses from Europe in addressing palliative care in children (Amery et al., 2012). Hence, the finding of the confidence level of nurses may not be generalized to nurses in Africa.

Treatment Outcomes

Children who are HIV-positive and are enrolled for palliative care are reported to have their psychological health well preserved (Lyon et al., 2008). Hence, after accepting palliative care provision, such children seem to be less psychologically stressed. Interesting findings have been reported on the characteristics of children who enrolled in pediatric palliative care. The study was a cross-sectional survey of the larger pediatric AIDS clinical trial group. Children who enrolled in palliative care were those who had a low quality of life score, in general, health perception, physical and social functioning (Lyon et al., 2008). According to the results of the study, no racial differences were detected amongst children enrolled for palliative care. This was unlike the findings in adults where racial differences were noted amongst adults who enrolled for palliative care (Lyon et al., 2008). However, it may be difficult to generalize findings of this study because of the low number of children enrolled in palliative care.

Lyon et al. (2008) showed the baseline characteristics of children who enrolled in palliative care despite the limitation of the low power of the study. However, a longitudinal follow-up and assessment of outcomes after provision of palliative care may be important to understand the impact of palliative care on children. A longitudinal follow-up and a first of its kind randomized study, was conducted by Lowther et al. (2014). However, the study was limited to adults. A replication of such a study may be important in children to assess treatment outcomes after providing palliative care.

A randomized trial in children and young adults infected with HIV has been initiated by Dallas et al. (2012). The methodology and design have been reported, and the study is on-going. The researchers have used the theory of transactional stress and coping and the theory of self-regulation to assess the efficacy of a family-centered approach in the management of HIV in children (Dallas et al., 2012). Findings of this study will be important as they will add to the understanding of the expectations of children and adolescents with the management of their illness.

Lowther et al. (2014) conducted a randomized controlled trial to assess the effectiveness of a nurse-led palliative care intervention for HIV-positive patients in an urban clinic in Mombasa, Kenya. The study focused on treatment outcomes and was referred to as the TOPCare study. It was a mixed method study which included qualitative interviews within a sub-set of the trial population (Lowther et al., 2014). Participants were recruited consecutively from the adult HIV population attending the clinic. A sample of 120 participants was recruited (Lowther et al., 2014). The sample size was selected based on a one point change in pain score and a 10 point change in the quality of life score (Lowther et al., 2015). In order to begin the screening, a random number table was used.

The researchers used predefined inclusion criteria which were: age above 18 years, a confirmed HIV-positive status, been on antiretroviral for at least 1 month, and able to consent to participation in the study (Lowther et al., 2014). Patients meeting the eligibility criteria were then asked to complete the African Palliative Care Association Palliative Care Outcome Scale (A-POS) to rate their pain and symptoms. For participants to be eligible, they had to report moderate to severe pain using the A-POS (Lowther et al., 2014). They were then taken through the informed consent process (Lowther et al., 2014).

Participants were allocated to either the control arm or the intervention arm using slips of papers which the researcher would blindly select. The control arm received standard HIV care and treatment at the clinic (Lowther et al., 2014). This would include assessment by a nurse, assessment by a doctor, receiving antiretroviral drugs prescriptions, adherence counseling, nutrition support, and home visits as detailed in the standard operating procedure offered to HIV-positive patients attending the comprehensive care clinic (Lowther et al., 2014).

Participants in the intervention arm had to visit the clinic at least seven times within the course of the study. The study lasted four months (Lowther et al., 2014). The intervention group received palliative care in addition to the standard care offered to all patients attending the HIV clinic (Lowther et al., 2014). Palliative care included referral to hospice and spiritual counseling for deserving patients. Palliative care was provided by nurses from the clinic who had received a two-week intensive training in palliative care by the Kenya Hospice and Palliative Care Association.

Self-reported questionnaires were used to assess treatment outcomes in both groups. The questionnaires included A-POS, the Medical Outcomes Study-HIV (MOS-HIV), the General Health Questionnaire-12 (GHQ-12), and the Client Services Receipt Inventory (CSRI; Lowther et al., 2014).

In a subsequent paper in 2015, Lowther et al. describe the outcome of the study. The primary outcome of the study was pain assessed through the A-POS (Lowther et al., 2015). Two thousand and seventy patients were screened for the study of which 271 were eligible. Of this number, 120 consented to participate in the study (Lowther et al., 2015). The most common reason for refusal to participation was the difficulty in reaching the clinic on a weekday for the additional appointments during the course of the study (Lowther et al., 2015). Both groups reported improvements in pain, mental and physical quality of life, and psychiatric morbidity. Significant within group improvement was noted in the intervention group in the ability to share feelings. (Lowther et al., 2015). A significant improvement was also noted in the mental health dimension of quality of life in the intervention arm of the study.

This trial was the first randomized study to show the impact of a nurse-led palliative care intervention in HIV-positive adults receiving antiretroviral therapy in a sub-Saharan African country (Lowther et al., 2015). The outcomes that showed improvements in the intervention arm had been reported in an earlier study to be the most burdensome to people living with HIV/AIDS in East Africa (Harding et al., 2014). The authors recommend a model integrating palliative care with standard HIV care in order to improve the quality of life of HIV-positive patients (Lowther et al., 2015).

Despite the evidence revealed in the study by Lowther et al. (2015), generalizability of the study may be reduced because of the reduced workload on the nurses in the intervention arm. These nurses cared only for patients in the intervention arm (Lowther et al., 2015). HIV clinics in sub-Saharan Africa are characterized by a large number of patients, and thus the nurses may not always be able to allocate additional time for palliative care (Amery et al., 2012). A single reliable and valid tool would be more appropriate. Also, the study was limited to adults and did not include children.

Spirituality

Spirituality has been investigated in some studies. A validated tool has been used to assess faith, spirituality, and meaning and purpose of peacefulness in life (Lyon et al., 2014). The tool was used to assess the variables at baseline and the end of three months. Children and adolescents showed a lower level of spirituality compared to their family members at baseline as well as the end of three months (Lyon et al., 2014). Almost all surveyed members disagreed that life lacks meaning and purpose, and a majority of them agreed that life had a reason (Lyon et al., 2014). A large proportion also disagreed that HIV was a punishment from God. Family members on their part thought that their child's illness had strengthened their faith in God. Adolescents seem to lack such beliefs. Disparities were also noted in the feeling of being able to forgive others, feeling of thankfulness, and feeling of love for others (Lyon et al., 2014).

At the end of three months, children and adolescents were noted to have a higher level of spirituality and lower levels of depression compared to baseline (Lyon et al., 2014). Levels of spirituality were not affected by gender in African American children

(Lyon et al., 2014). The study revealed that spirituality and depression had an inverse relationship with depression decreasing with high levels of spirituality. Similar findings were noted by Lowther et al. (2014) in Kenya. However, the Kenyan study was for adults. One explanation for the findings of the study by Lyon et al. (2014) is the generational differences in beliefs. Young adults seem to be less forgiving than their family members. However, the position was different post-intervention at the end of the three-month period. At baseline, young adults seem to be annoyed and would not want to forgive the individual responsible for their infection. However, at the end of the three-month period, the same individual became more forgiving and believed that the illness had, in fact, strengthened their belief in God.

Spirituality also showed a positive correlation with adherence to HIV/AIDS treatment (Lyon et al., 2014). Other areas that showed improvements were psychological and physical well-being (Lyon et al., 2014). Nevertheless, the study had important limitations. Selection bias cannot be ruled out when interpreting findings of this study. Individuals who consented to participate in this study may already have been spiritually inclined compared to those who refused participation. Self-reporting of feelings opens further room for bias in the interpretation of study results. The study had a small sample size that could result in a low power and patients with depression were not included in the study (Lyon et al., 2014).

Park and Nachman (2010) compared adherence to antiretroviral therapy in HIV-infected children who had strong religious beliefs with infected children who had lower levels of beliefs and religious practices. The Stony Brook University study showed that higher levels of adherence were reported in children with strong religious beliefs and practices compared to those with low levels of religious beliefs (Park & Nachman, 2010). The authors concluded that spirituality was an important factor in determining adherence levels in the pediatric population. Affiliation to religion and spirituality played an important role in adherence as well as self-esteem of patients (Park & Nachman, 2010). Findings on depression and adherence were similar to those noted in a later study by Lyon et al. (2014). Children and young adults with strong religious beliefs and spirituality had lower levels of depression and higher levels of adherence in both studies (Lyon et al., 2014; Park & Nachman, 2010). Spiritual care is an integral part of palliative care offered to children (Harding et al., 2014). The benefits of spiritual care have been demonstrated in these studies that have shown the important role it plays in the well-being of the child.

Wiener et al. (2012) reported that children believe that they are mortal. However, becoming aware of their terminal illness may demoralize them and make them feel they would not be able to achieve what they wanted to in life (Wiener et al., 2012). Children further wish to be remembered long after they are gone (Wiener et al., 2012). Therefore, the discussion on end of life management and end of life care would be important to raise the morale of such children and improve their well-being.

Use of Validated Tools

Connor et al. (2014) attribute the lack of adequate information on pediatric palliative care to unavailability of an accepted validated tool to collect information on variables relevant to palliative care in children. The African Palliative Care Assessment

(APCA) tool has been used in some studies (Connor et al., 2014). However, such studies are few. The tool used by Harding et al. (2014) was tested in one large and one small pharmacy. However, the focus of their study, and hence their tool, was to collect information on the availability of essential drugs used in palliative care in the pharmacies in sub-Saharan Africa (Harding et al., 2014). The tool was designed to identify operational aspects of palliative care instead of treatment outcomes.

The first pediatric version of APCA was designed and reported by Downing et al. (2012). This is one validated tool and can be applied to African children (Harding et al., 2014). However, there have been no studies reporting its application on treatment outcomes in children. The Five Wish document has been accepted for use in the 40 USA states and the District of Colombia (Wiener et al., 2008). This document provides patients the opportunity to express the type of end of life care they desire. The document has legally been accepted for use in the USA (Wiener et al., 2008). However, no studies have documented its application in African children.

The functional well-being scale of functional assessment of chronic illness therapy is a validated tool and was used by Lyon et al. (2014) on African – American children in the United States of America. The tool was applied to assess spirituality in children and young adults who are HIV-positive (Lyon et al., 2014). The tool comprises a 23-item scale that includes amongst other variables, the assessment of faith and meaning of peacefulness in life (Lyon et al., 2014). Lyon et al. (2014) also used the Beck anxiety inventory, the Beck depression inventory, and the pediatric quality of life inventory.

Pediatric Quality of Life Inventory

Health-related quality of life (HRQOL) has been accepted as an important health outcome in clinical trials, clinical practice, and research and evaluation in health care services (Varni et al., 2003; Varni et al., 2010). The terms health status, functional status, and HRQOL are used interchangeably (Varni et al., 2003). However, it is important to note that the former two refer to physical functioning which is one aspect of the HRQOL. The HRQOL also includes emotional, social, and role functioning as its other aspects (Punpanich et al., 2010; Varni et al., 2003). HRQOL was introduced into HIV/AIDS research on quality of life of patients in 1990 (Wu et al., 1990). At first, it was used to assess the impact of antiretroviral therapy on the well-being of patients. Subsequently, it was used to report disease burden, monitor health changes, and evaluate health care programs (Hays, Cunningham, & Sherbourne, 2000).

The PEDSQL inventory is a tool designed to assess the HRQOL in children (Varni, Seid, & Rode, 1999). The tool is a practical, validated, generic measure of the quality of life of children (Punpanich et al., 2010). It can be used to assess risk, track health status, and measure treatment outcomes in children (Varni et al., 1999). The tool can be used to systematically assess the child’s and the parent’s perception of the quality of life of children with chronic conditions (Varni et al., 1999). The tool is based on a modular approach consisting of 15 items of core measure of global health related quality of life and eight items assessing specific symptom or treatment domain (Varni et al., 1999). Historically, it was derived from data collected from 291 children diagnosed with cancer (Varni et al., 1999).

Reliability and validity of the PEDSQL have been tested in a number of studies (Varni et al., 1999; Varni et al., 2002; Varni et al., 2003; Varni & Limbers, 2009; Varni, Seid, & Kurtin, 2001). There are a number of benefits associated with the PEDSQL. It is brief, practical, flexible, developmentally appropriate, multidimensional, reliable, valid, and responsive to clinical change over time (Eiser & Morse, 2001; Varni et al., 1999; Varni et al., 2003, Varni et al., 2010; Xu et al., 2010). The tool consists of a child self-report for ages 5 to 7, 8 to 12, and 13 to18 and a parent proxy report for ages 2 to 4, 5 to 7, 8 to 12, and 13 to 18.

The dimensions of health tested using the PEDSQL have been derived from WHO (Varni et al., 1999). The scale has 23 items grouped into four major categories (multidimensional scales): physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). Scores are divided into two categories (summary scores): physical health summary score (eight items) and psychosocial health summary score (15 items). The total scare score is 23 items.

PEDSQL has been tested in a number of countries and different languages (Punpanich et al., 2010; Xu et al., 2010). In Thailand, it has been used to test the validity and reliability of disease-specific measurement tools such as the Thai Quality of Life in Children (THQLC). The latter was used to assess the quality of life in HIV-positive children. The PEDSQL was used as a standard to check for internal consistency (Punpanich et al., 2010). Results revealed that both THQLC and the PEDSQL overall scores correlated with the child's self-rated severity of illness and the caregiver's rated overall quality of life (Punpanich et al., 2010). Overall scores of both tools correlated with clinical and immunologic categories of the US-CDC classification system (Punpanich et al., 2010).

There was adequate convergent validity between the two instruments, and there was no consistent systematic bias (Punpanich et al., 2010). However, the THQLC had lower internal consistency reliability in the physical functioning domain. Nevertheless, the THQLC had an additional life perspective domain and may have been framed in a manner considered pertinent to the local context and culture. One limitation of this study was that it was cross-sectional in nature hence the authors could not test whether the instruments differed in their ability to detect changes over a period of time (Punpanich et al., 2010).

Xu et al. (2010) conducted a study in China to identify major factors influencing the HRQOL of children diagnosed with HIV/AIDS. The study was conducted in the rural areas of Yunnan in China (Xu et al., 2010). The authors enrolled children from HIV-affected families and HIV-unaffected families in the study and used the Chinese version of the PEDSQL life inventory. This was also a cross-sectional study. Affected families were those who had a child aged between 8 and 18 years of age, was HIV-negative, and the child had at least one parent who was HIV-positive or had lost at least one parent to HIV/AIDS (Xu et al., 2010). Unaffected families were those had a child aged between 8 and 18 years and had no HIV confirmed parent. The child self-report and the parallel parent proxy report were administered to all participants.

Results revealed that children who had a parent living with HIV/AIDS or who had lost either parent to HIV/AIDS had lower quality of life scores than children who did not have an HIV confirmed parent (Xu et al., 2010). The scores were significantly lower in total scores, psychosocial functioning, school functioning, and emotional functioning. The parents' proxy report showed lower scores in affected families in total scores, psychosocial functioning, emotional functioning, and social functioning (Xu et al., 2010). This study revealed that a child's self-esteem, awareness of the parent's HIV status, and the duration of time spent by the caregiver with the child affected the quality of life of the child (Xu et al., 2010). Findings were consistent with older studies where the association of self-esteem and psychological problems were assessed (Ravaeis, Seigel, & Karus, 1999; Sandler et al., 2003).

It is interesting to note that children living with grandparents showed better quality of life scores, particularly in psychosocial domains, compared to children living with their parents. This finding contradicts findings of earlier studies conducted in other countries (Joslin & Harrison, 2002; Juma, Okeyo, & Kidenda, 2004; Ozuah, 2003). One explanation for this finding could be that after the death of parents, grandparents may take a greater interest in the well-being of the child than they would otherwise. The study by Juma et al. (2004) was conducted in Kenya and showed that children living with grandparents in that part of the world had a lower quality of life. Children in sub-Saharan Africa have to care for their sick parents or grandparents. In some instances, they even have to take up financial responsibilities for the entire family (Connor et al., 2014).

Hence, the findings by Xu et al. (2010) may not be generalized to children in sub-Saharan Africa.

Bomba et al. (2010) conducted a study in Italian children living with HIV/AIDS. The authors aimed to assess health related quality of life, social competence, and behavioural problems in children living with HIV/AIDS in Italy. In addition to the PEDSQL life inventory, the authors also used the Child Behaviour Checklist which assessed behavioural problems (Bomba et al., 2010). The assessment revealed that HIV-infected children had lower physical and psychosocial health functioning especially at school compared to non-HIV children (Bomba et al., 2010).

A similar study conducted in Delhi around the same time assessed the reliability and validity of the PEDSQL in HIV-positive children. The authors used the PEDSQL to assess the HRQOL in HIV-infected and un-infected children, the HRQOL in children on antiretroviral therapy, and the HRQOL of children living at home and those living in institution-based care homes (Banerjee, Pensi, & Banerjee, 2010). Results showed that the PEDSQL is an acceptable and a valid measure of HRQOL in HIV-infected children. HIV-infected children had lower scores in HRQOL compared to un-infected children. HIV-positive children on antiretroviral had better scores than children who were not on antiretroviral therapy (Banerjee et al., 2010). Children living at home had lower scores on emotional and social functioning compared to those living in institution-based care homes (Banerjee et al., 2010).

The relevance of the PEDSQL in assessing HRQOL in HIV-positive patients was documented in these studies. Palliative care lays emphasis on the emotional, psychosocial, and physical well-being of the patient. These aspects are covered by the PEDSQL (Varni et al., 2003). Its use in the assessment of the impact of palliative care provision in HIV-positive patients is thus justified (Lyon et al., 2014).

Summary

According to studies conducted on patients diagnosed with HIV it was revealed that despite antiretroviral initiation, people living with HIV and AIDS continue to suffer the symptom burden (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). In fact, people living with HIV/AIDS have a higher burden of physical problems compared with the HIV-negative population (Harding & Sherr, 2014; Parker et al., 2014).

Greater than 90% of all children infected with HIV worldwide are in sub-Saharan Africa (Harding et al., 2014). HIV is a major cause of deaths in children in sub-Saharan Africa (Connor et al., 2014). Children residing in sub-Saharan Africa have to face additional challenges compared to their counterparts (Connor et al., 2014). Children in sub-Saharan Africa have to care for their sick parents or grandparents. In some instances, they even have to take up financial responsibilities for the entire family (Connor et al., 2014). This increases the psychosocial stress on the children. Such stress needs to be addressed.

Palliative care is an integral part of the holistic care that can be offered to HIV-positive patients (WHO, 2011). It includes addressing the psychosocial, spiritual, and social needs of the child. The care extends beyond the index patient to the family as a whole. Physical and mental well-being of the child is an essential component of palliative

(WHO, 2011). Palliative care has shown benefits in patients with conditions such as asthma, COPD, stroke, health failure, diabetes, and cancers (Ali et al., 2003; Bakitas et al., 2009; Brown, 1992; Fogarty et al., 1999; Forster et al., 2012; Higginson et al., 2010; Kotses et al., 1995; Miller et al., 2005; Rabow et al., 2004; Temel et al., 2010; ZuWallack, Meek, & Jain, 2011). Few studies have shown benefits of individual aspects of palliative care in HIV-positive adults (Green et al., 2010; Harding et al., 2010, Harding et al., 2013; Lowther et al., 2014). Models of palliative care are also limited in the literature despite comprehensive programs existing in many countries (Harding et al., 2014; Lowther et al., 2014). Such reported models have shown treatment outcomes in adults and not in children. There is a paucity of information on care models and treatment outcomes of palliative care in HIV-positive children.

One reason for the paucity of information for children could be the difficulty in assessing pain and other symptoms in children (Amery et al., 2010). The limited number and scope of the validated tools could also have contributed to this (Connor et al., 2014). The PEDSQL and the pediatric version of the APCA tool are examples of available options.

HRQOL was introduced for assessment of the quality of life of HIV-positive patients in 1990 (Wu et al., 1990). The PEDSQL inventory is a tool designed to assess the HRQOL (Varni et al., 1999). The tool is based on a modular approach consisting of 15 items of core measure of global health related quality of life and eight items assessing specific symptom or treatment domain (Varni et al., 1999). Reliability and validity of the PEDSQL have been tested in a number of studies (Varni et al, 1999; Varni et al., 2002;

Varni et al., 2003; Varni & Limbers, 2009; Varni et al., 2010). The PEDSQL has been used in some studies on HIV-positive children to assess HRQOL. Components of palliative care are similar to those of the HRQOL. Its use to assess impact of palliative care on the quality of life of HIV-positive patients is thus justified (Lyon et al., 2008).

HIV treatment in children started much later after it was rolled out in adults (CDC, 2015). This could be one reason why fewer models have been reported in children (Wallis et al., 2009). Care models in the adult population evolved through best practices reported in the literature. The same did not apply for children. Palliative care is not a new concept for non-HIV patients. Even in HIV adult patients, some aspects of supportive care were offered before the advent of antiretroviral therapy (ART). It is possible that focus shifted from supportive care to antiretroviral therapy after the latter was introduced on a wide scale. Nevertheless, some aspects of palliative care continue to be offered in HIV clinics. It is the integration of a complete palliative care package within an HIV clinic that is limited in the literature although the need has been stated by several researchers (Farrant et al., 2012; Harding et al., 2010; Harding et al., 2012, Merlin et al., 2012; Perry et al., 2013).

Longitudinal follow-up of adults receiving palliative care in a randomized controlled trial has been conducted in Kenya (Lowther et al., 2014). In this study, the authors demonstrate significant improvement in mental health dimension of quality of life when palliative care is provided in addition to standard HIV care. The study provides a strong foundation of an integrated model in adults living with HIV/AIDS. Considering that HIV-positive children have an additional burden to bear with (Connor et al., 2014) and that unique validated tools are required to assess quality of life in children, a study specific to children is required to demonstrate the impact of palliative care in HIV-positive children.

Baseline characteristics and some treatment outcomes such as reduction in stress have been demonstrated in children (Lyon et al., 2008). An assessment of the HRQOL of HIV-positive children receiving comprehensive palliative care alongside antiretroviral therapy would reveal empirical evidence on treatment outcomes. The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy in Kenya, sub-Saharan Africa. Chapter 3 will include the research design and rationale, detailed methodology, and threats to validity.

Chapter 3: Research Method

Introduction

Children diagnosed with HIV/AIDS in sub-Saharan Africa face additional physical and mental burden compared to HIV-negative children (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). While this compromises the quality of life of individuals living with HIV/AIDS, it also threatens the continued success of the roll out of antiretroviral therapy due to the association of depression and distress arising as a result of antiretroviral toxicity (Braithwaite et al., 2008). Palliative care lays emphasis on holistic patient-centered care including the impact of illness on the family, and recognition of the importance and interdependence of physical, psychological, social, and spiritual symptoms alongside antiretroviral therapy (WHO, 2006).

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. I used a quantitative research mode and conducted chart reviews of children who had been on antiretroviral therapy and had received palliative care. I compared treatment outcomes with children who had been on antiretroviral therapy and had received standard HIV care and treatment but no palliative care.

This chapter will include a description of the research design and rationale. I will provide an in-depth description of the study methodology including population, sampling and sampling procedures, procedures for recruitment, participation, and data collection.

The instrumentation and operationalization of constructs, data analysis plan, threats of internal and external validity, and ethical procedures will also be included in the chapter.

Research Design and Rationale

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. I studied two main areas that included psychosocial health and physical health in children on antiretroviral therapy. The independent variable was the type of care (palliative vs. standard care) provided by nurses, and the dependent variables were psychosocial health and physical health.

I used a cross-sectional design to study the impact of the independent variable (type of care) on the dependent variables (psychosocial health and physical health). In social sciences, cross-sectional study designs are amongst the most prominent study designs (Frankfort-Nachmias & Nachmias, 2008). In such a design, a sample is randomly selected from the population and asked a set of questions (Frankfort-Nachmias & Nachmias, 2008). Hence, a survey design is mostly deployed in such studies (Frankfort-Nachmias & Nachmias, 2008). The design comprises a single period of observation without any follow-up, and a snapshot of the population is obtained (Frankfort-Nachmias & Nachmias, 2008).

Cross-sectional study designs have several advantages. They are less expensive to conduct compared to longitudinal studies (Frankfort-Nachmias & Nachmias, 2008). The studies are also less time consuming compared to other study designs. Results of such studies can be generalized if a representative sample is used from the population

(Aschengrau & Seage, 2008). Researchers can determine relationships between variables using a cross-sectional study design (Crosby et al., 2013). However, there are some limitations of cross-sectional study designs particularly when causal relationships need to be established (Aschengrau & Seage, 2008). They also provide limited information on directionality (Frankfort-Nachmias & Nachmias, 2008). Despite this limitation, cross-sectional study designs can enable researchers to describe patterns of relationship between variables (Frankfort-Nachmias & Nachmias, 2008).

In this study, I compared the HRQOL of children who have received or are receiving palliative care to HIV-positive children who were not receiving palliative care. A snapshot of the two – those receiving palliative care and those not receiving palliative care – was required for the comparison; hence, a cross-sectional study design was appropriate. Aspects of palliative care have been described using cross-sectional study designs in other studies (Connor et al., 2014, Harding et al., 2014, Lyon et al., 2008, Park & Nachman, 2010, Wiener et al., 2012). I conducted chart reviews of children participating in this study, and information on psychosocial health and physical health was derived from the PEDSQL inventory.

The PEDSQL inventory is a tool designed to assess the HRQOL in children (Varni et al., 1999). The tool is a practical, validated, generic measure of the quality of life of children (Punpanich et al., 2010). It can be used to assess risk, track health status, and measure treatment outcomes in children (Varni et al., 1999). In this study, treatment outcomes and HRQOL are important; hence, the use of the PEDSQL inventory. The

PEDSQL has been used in similar study designs in children (Eiser & Morse, 2001; Varni et al., 1999; Varni et al., 2003, Varni et al., 2010; Xu et al., 2010).

Children receiving palliative care enrolled in this study had received palliative care for a minimum of 3 months. I abstracted health scores from the clinic charts of children. Because my aim was to assess these variables at a particular time period in children receiving palliative care and compare them with children receiving standard HIV care, a cross-sectional study design remained the appropriate choice.

Methodology

Population

I conducted this study at a single outpatient HIV center providing care and treatment services to HIV-positive children. The hospital is a not-for-profit registered nongovernmental organization (NGO) in Kenya that has been in operation for the last 35 years. It is located strategically in the heart of the rural area in Mombasa, Coast Province, where it can serve the mostly underserved populations of the district. However, the center is visited by individuals from all cadres and social classes. The center has a specialized HIV/AIDS comprehensive care center (CCC) providing care and treatment since 2004. At the time of the study, more than 16,000 people living with HIV/AIDS (PLWHA) had been enrolled at the center and were being followed up on care and treatment. About 9,000 patients had been started on antiretroviral therapy. The care and treatment offered to PLWHA are free and is supported by the PEPFAR funds. This includes HIV testing, laboratory monitoring, treatment, and prophylactic medicine.

Standard operating procedures which have been prepared from guidelines by the National AIDS and STIs Control Program are used at the hospital to check the eligibility of patients on antiretroviral therapy. The CD4 level is used to determine whether to start ART or not. Once a patient meets the CD4 cut off, social criteria are then used to determine eligibility to ART. The current guideline is to initiate ART in patients with a CD4 count of fewer than 350 cells. Patients diagnosed with HIV/AIDS are routinely followed up at the CCC at the hospital which runs 5 days a week.

The Ministry of Health's (2014) national guidelines provide the following recommendations for initiating antiretroviral therapy in HIV-positive children:

1. All HIV-infected children below 10 years of age are initiated on antiretroviral therapy regardless of WHO stage and CD4 count.
2. All HIV-infected children above 10 years of age should be initiated on antiretroviral therapy regardless of the WHO stage if the CD4 count is less than 500 cells/mm^3
3. All HIV-infected children above 10 years of age should be initiated on antiretroviral therapy regardless of the CD4 count if they are classified in WHO Stage 3 or Stage 4, or have the hepatitis B virus or tuberculosis.

Additional guidelines at the hospital include:

1. Determining and understanding the information from triage and nutrition.
2. Performing a thorough physical examination in order to identify any illnesses.

3. Verifying the past medical history, family background, previous antiretroviral (ARV) drug use, alcohol, and substance abuse (if applicable), and availability of a stable caregiver.
4. Counseling the caregiver on the importance of adherence and disclosure.
5. If the child is eligible for antiretroviral therapy based on national guidelines, the child is referred to the adherence counselor.
6. Baseline laboratory tests according to the national guidelines are requested.
7. The child is initiated on cotrimoxazole according to the weight.
8. Opportunistic infections are identified and treated.
9. If eligible according to national guidelines, an eligibility form is completed and presented at the next eligibility meeting.
10. The clinicians provide their recommendations on the first line regimen. This should take into account any previous exposure to ARVs and any other contraindications. Once approved by the committee, the child may be initiated on ARVs after thorough preparation.

This study did not involve collecting data directly from participants. The children registered for HIV care and treatment at this facility were Kenyans. There was no majority ethnic group amongst the children who accessed care at the center. HIV-positive children are followed from diagnosis to 15 years of age in this center. After this age, they are transferred to the adult clinic. Children between aged between 5 and 15 years were eligible to be enrolled in this study if they had been on antiretroviral therapy for 3 months. The age group was selected from studies in which the PEDSQL had been validated (Ewing, King, & Smith, 2009; Ferreira et al., 2014).

Sampling and Sampling Procedures

All pediatric patients aged between 5 and 15 years and receiving antiretroviral therapy at the hospital were eligible for chart review. There were no direct patient interviews. I collected all data through chart reviews. The hospital offers palliative care to all children receiving antiretroviral therapy. However, children and parents have the option of opting out of this service. Hence, there is a group that receives palliative care and there is a group that receives standard HIV care and treatment. The inclusion criteria for the study was HIV-positive children receiving antiretroviral therapy for at least 3 months, of any race and ethnicity, aged between 5 and 15 years and receiving palliative care and standard care or standard care alone for a period of at least 3 months. Figure 1 shows the category of children eligible for the study.

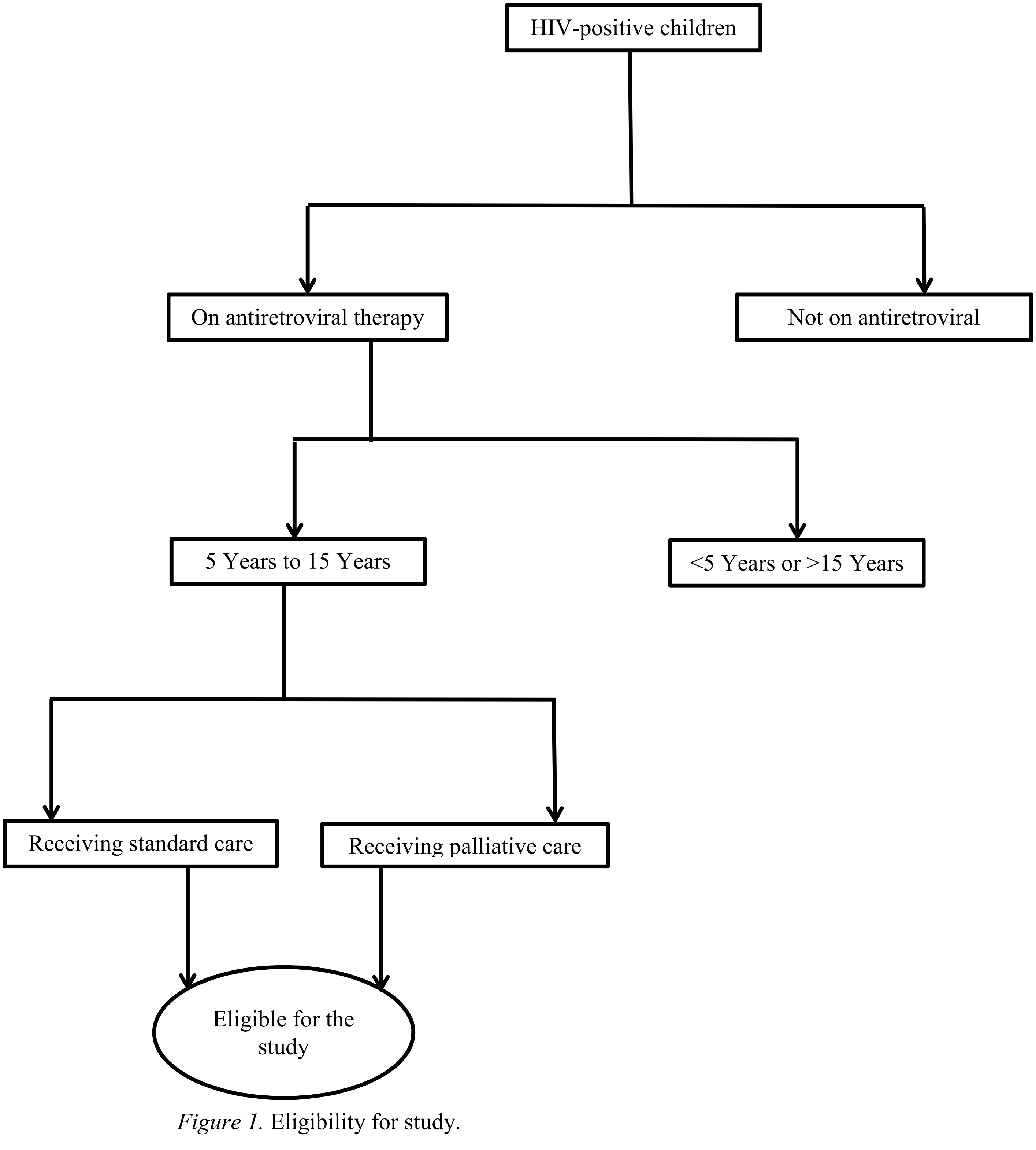

Figure 1. Eligibility for study.

The statistics available from the hospital as at December 2015 are shown in Table 1.

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Table 1

HIV Statistics from the Hospital

Description	Numbers
Number of individuals (adults and children) ever enrolled on care and treatment	21,226
Number of individuals (adults and children) currently on care and treatment	11,730
Number of individuals (adults and children) ever initiated on antiretroviral therapy	15,726
Number of individuals (adults and children) currently on antiretroviral therapy	11,455
Number of children ever enrolled on care and treatment	1,843
Number of children currently on care and treatment	949
Number of children ever initiated on antiretroviral therapy	1,351
Number of children currently on antiretroviral therapy	949

In order to calculate the minimum sample size, G*Power Calculator (Version 3.1.9.2) was used. Lowther et al. (2014) used a medium effect size of .5 in a longitudinal study to assess treatment outcomes in adult HIV-positive patients receiving palliative care. Lowther et al. used a power of 90% in a study to assess treatment outcomes of palliative care in HIV-positive adults in Kenya. Banerjee et al. (2010) used all children attending the pediatric HIV clinic when comparing the HRQOL of such children with

HIV-negative children. Varni et al. (2003) used an electronic mail survey sent to 20,031 families in the state of Michigan. This comprised all families whose data were centrally available.

There are no preexisting thresholds for clinically significant change in the literature on HIV-positive children. In the doctoral thesis, Lowther et al. (2014) used a medium effect size of .5 for the longitudinal study in adult HIV population receiving palliative care. This justification was used in this study and a medium effect size of 0.5 was used. Lowther et al. (2012) used a sample size calculated based on a two-tailed test and a *p* value of <.05.

A medium effect size of .5 (Laerd Statistics, 2016) was thus used to determine the sample size (Faul, Erdfelder, Buchner, & Lang, 2009). Using an alpha of .05 and a power of .9, the exact sample size required was determined using the following steps.

Select *t* tests from the test family according to RQ1 and RQ2 (regression tests [RQ3] cannot be used for this calculation, as there was no adequate available information from previous studies to calculate the needed sample size). From the test statistics select means: difference between two independent means (two groups). In the type of power analysis select a priori: compute required sample size given alpha, power, and effect size. The input parameters of alpha (.05), power (.9), allocation ratio (1), and effect size (.5) are entered. The required sample size would be 172 with 86 children in each arm. This means that a minimum of 172 charts were to be reviewed in the study if an alpha of .05 and a power of 90% are used in the study. This was the minimum sample size required.

Procedures for Recruitment, Participation, and Data Collection

Children aged between 5 and 15 years are school going children. The study thus focused on a specific age group of children. PEDSQL has been validated in this group to determine the quality of life (Ewing et al., 2009; Ferreira et al., 2014). The hospital provides palliative care to children with an opt-out option. Children and parents have the option of refusing to participate in the palliative care program. Hence, there is an arm that receives standard HIV care and treatment and there is an arm that receives palliative care in addition to standard HIV care at the center.

The HIV center operates as an outpatient center and operates from 8.00 a.m. to 5.00 p.m. 5 days a week. HIV-positive children are referred from the voluntary counseling and testing center, the maternal and child health center, the outpatient center, or are referred to the HIV clinic from neighboring voluntary counseling and testing centers. All children undergo a confirmatory HIV test upon registration. All patient charts are stored in the medical records department. Each child has a unique identifier which is recorded on the patient chart. Study numbers were assigned to each patient chart by the medical records staff. Names of patients were not known to me. The study numbers of eligible patients and the relevant information were extracted from the patient chart. All information was de-identified from the patient and was not traceable to the individual patient. The following information was retrieved from the patients' charts: type of treatment (palliative vs. standard), date of birth, date of start of ART, nadir CD4 count (prior to provision of palliative care), most recent CD4 count, psychosocial health summary score, and physical health score.

I collected information at a single point in time. There was no follow-up information collected. I entered the information collected into an Excel spreadsheet, transferred the information to an SPSS sheet and then returned the chart to the medical records department. No additional information was retrieved from the chart.

The study approach was a retrospective chart review. In this method, prerecorded patient data are used to answer research questions (Matt & Mathew, 2013). While the method is common in research studies, there is a likelihood of lack of sound methodological standards (Gilbert, Lowenstein, Kozoiol, Barta, & Steiner, 1996). Possible areas where methodological omissions may occur in this method include: failure to articulate research questions, not considering sampling issues a priori, lack of adequate operationalization of variables, failure to provide adequate guidance to data abstractors, lack of well-articulated inclusion and exclusion criteria, not addressing reliability – interrater and intrarater, not performing a pilot test, and not addressing confidentiality issues (Matt & Mathew, 2013).

In order to address such possible areas of concerns in a retrospective chart review, I trained data abstractors on data collection from the charts. I conducted a pilot study prior to initiation of data collection proper. Interrater reliability was tested by asking at least two data abstractors to abstract data from the same chart. Intrarater reliability was tested by getting a data abstractor to abstract data from the same chart on two different occasions.

Instrumentation and Operationalization of Constructs

The PEDSQL inventory is a tool designed to assess the HRQOL in children (Varni et al., 1999). The tool is a practical, validated, generic measure of the quality of life of children (Punpanich et al., 2010). It can be used to assess risk, track health status, and measure treatment outcomes in children (Varni et al., 1999). The tool can be used to systematically assess the child's and the parent's perception of the quality of life of children with chronic conditions (Varni et al., 1999). The tool is based on a modular approach consisting of 15 items of core measure of global HRQOL and eight items assessing specific symptom or treatment domain (Varni et al., 1999). Historically, it was derived from data collected from 291 children diagnosed with cancer (Varni et al., 1999).

Reliability and validity of the PEDSQL have been tested in a number of studies (Varni et al., 1999; Varni et al., 2002; Varni et al., 2003; Varni & Limbers, 2009; Varni et al., 2010). There are a number of benefits associated with the PEDSQL. It is brief, practical, flexible, developmentally appropriate, multidimensional, reliable, valid, and responsive to clinical change over time (Eiser & Morse, 2001; Varni et al., 1999; Varni et al., 2003, Varni et al., 2010; Xu et al., 2010). The tool consists of a child self-report for ages 5 to 7, and 8 to 12, 13 to 18 and a parent proxy report for ages 2 to 4 ,5 to 7, 8 to 12, and 13 to 18.

The dimensions of health tested using the PEDSQL have been derived from WHO (Varni et al., 1999). The scale has 23 items grouped into four major categories (multidimensional scales): physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). Scores are divided into two categories (summary scores): physical health summary score (eight items) and psychosocial health summary score (15 items). The total scare score is 23 items.

PEDSQL has been tested in a number of countries and in different languages (Punpanich et al., 2010; Xu et al., 2010). In Thailand, it has been used to test the validity and reliability of disease-specific measurement tools such as the THQLC. The latter was used to assess the quality of life in HIV-positive children. The PEDSQL was used as a standard to check for internal consistency (Punpanich et al., 2010). Xu et al. (2010) conducted a study in China to identify major factors influencing the HRQOL of children diagnosed with HIV/AIDS. The study was conducted in the rural areas of Yunnan in China (Xu et al., 2010). Bomba et al. (2010) conducted a study in Italian children living with HIV/AIDS. The authors aimed to assess health related quality of life, social competence, and behavioural problems in children living with HIV/AIDS in Italy. A similar study conducted in Delhi around the same time assessed the reliability and validity of the PEDSQL in HIV-positive children. The authors used the PEDSQL to assess the HRQOL in HIV-infected and un-infected children, the HRQOL in children on antiretroviral therapy, and the HRQOL of children living at home and those living in institution-based care homes (Banerjee et al., 2010).

Research Questions

RQ1: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only?

$H_0$1a: There is no significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1a: There is a significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only

$H_0$1b: There is no significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1b: There is a significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

$H_0$1c: There is no significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1c: There is a significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

RQ2: Is there a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only?

$H_0$2: There is no significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A2: There is a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

RQ3: Is there a difference in psychosocial health and physical health between children on antiretroviral therapy who receive palliative care and those who do not receive palliative care when controlled for age, gender, duration on antiretroviral therapy, and CD4 count?

$H_0$3: There is no significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count

H_A3: There is a significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count

Variables

The following variables were of interest in the study: type of care (palliative vs. standard), age, gender, duration on antiretroviral therapy, CD4 count, psychosocial health summary score, and physical health score. A cross-sectional study design was used to study the impact of the independent variable (the type of care) on the dependent variable (psychosocial health and physical health). Variables that were controlled were age, gender, and duration on antiretroviral therapy. The variables with the appropriate level of measurement and relevant research question are presented in Table 2.

Table 2

Variable, Level of Measurement, and Research Question

Variable	Level of measurement	Research question
Type of care	Nominal	RQ1, RQ2
Age	Continuous (years)	RQ3
Gender	Categorical	RQ3
Duration on antiretroviral therapy	Continuous (months)	RQ3
CD4 count	Continuous	RQ3
Psychosocial health summary score	Ordinal (0, 25, 50, 75, 100)	RQ1
Physical health score	Ordinal (0, 25, 50, 75, 100)	RQ2

Operationalization

The independent variable in this study was the type of care. The dependent variables were psychosocial health summary score and physical health score. Variables that were controlled were age, duration on antiretroviral therapy, gender, and age of the child.

The participant number was assigned on a consecutive basis starting from number 1. Age was recorded as a two digit number. Gender was marked as male or female. Duration of antiretroviral therapy was calculated in months by obtaining the start date of ART from the chart.

Nadir CD4 count was recorded as the last CD4 count before palliative care intervention was offered to the child. For children who opted not to receive palliative care, nadir CD4 was the last CD4 at the time when palliative care intervention was being rolled out in the clinic. The last CD4 count was the most recent CD4 count at the time of the chart review.

Psychosocial and physical health summary scores were derived from the PEDSQL. The scale has 23 items grouped into four major categories (multidimensional scales): physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). Scores are divided into two categories (summary scores): physical health summary score (eight items) and psychosocial health summary score (15 items). The total score is 23 items.

Psychosocial health summary score was the mean of emotional, social, and school functioning scales from the PEDSQL. In the PEDSQL, items are reversed score (Varni et al., 1999). The 0 to 4 scale items were reversed as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. The higher scores thus indicated better HRQOL. Physical health summary score was also computed as reverse scores and was the same as the physical functioning scale score.

Data Analysis Plan

The following variables were of interest in the study and were obtained from the chart: date of birth, gender, date of start on antiretroviral therapy, nadir CD4 count (prior to provision of palliative care), most recent CD4 count, psychosocial health and physical health. These variables were recorded in an Excel worksheet which had columns for each variable. Data were then transferred to Statistical Package for Social Sciences (SPSS) Version 21 which was used in executing data analysis. First, descriptive analysis was conducted to present the age, gender, CD4 count, and duration on antiretroviral therapy. Missing values were determined and recorded.

The mean age of children receiving palliative care was compared to the mean age of children who opted not to receive palliative care. Similarly, duration on antiretroviral therapy of children receiving palliative care was compared to the duration on antiretroviral therapy of children not receiving palliative care. Mean nadir CD4 count of children receiving palliative care was determined. Similarly, the mean CD4 count of children who opted not to receive palliative care was also be determined. An independent *t* test was to be used to determine the difference in the CD4 count in each category, if CD4 was normally distributed. Since the data were not normally distributed, a Mann-Whitney U test was applied.

Psychosocial health and physical health scores were compared between the group receiving palliative care and the group not receiving palliative care using the Mann – Whitney U Test since the assumption for parametric independent *t*-test were not met. A model using linear regression was to be made comparing psychosocial health and physical health in each group (palliative vs. standard care) and controlling for age, gender, duration on antiretroviral therapy, and CD4 count. Since the assumptions for linear regression were not met, the dependent variable were recoded into a binary variable (high and low PEDSQL score) and logistic regression was used.

Data cleaning and screening was conducted prior to conducting the analysis. Missing values were recorded. Possible sources of errors included an incorrect recording from the charts and transcription errors. These were checked for prior to the analysis. If the PEDSQL scores were missing, then the patient was excluded from the analytic sample. Similarly, where other variables were missing, the scores were not be included in the analytic sample.

A summary of the statistical tests and the relevant research questions and hypotheses are provided in Table 3.

Table 3

Research Questions, Hypotheses, and Appropriate Statistical Tests

Research Question	Hypothesis (H_A)	Variables	Statistical Procedure
RQ1-Quantiative: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only?	There is a significant difference in emotional functioning between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only	IV – type of care DV – emotional functioning	*t* test or Mann-Whitney U test
RQ1-Quantiative: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only?	There is a significant difference in social functioning between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only.	IV – type of care DV – social functioning	*t* test or Mann-Whitney U test

(table continues)

Research Question	Hypothesis (H_A)	Variables	Statistical Procedure
RQ1-Quantiative: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only?	There is a significant difference in school functioning between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only.	IV – type of care DV – school functioning	*t* test or Mann-Whitney U test
RQ2-Quantitative: Is there a significant difference in physical health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only?	H_A: There is a significant difference in physical health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only.	IV – type of care DV – physical health score	*t* test or Mann-Whitney U test

(table continues)

Research Question	Hypothesis (H_A)	Variables	Statistical Procedure
RQ3-Quantitative: Is there a difference in psychosocial health and physical health between children on antiretroviral therapy who receive palliative care and those who do not receive palliative care when controlled for age, gender, duration on antiretroviral therapy and CD4 count?	There is a significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count	IV – type of care DV – psychosocial health and physical health scores	Linear or logistic regression

Threats to Validity

Cross-sectional study designs are limited in establishing causal relationships and directionality (Frankfort-Nachmias & Nachmias, 2008). Cross-sectional study designs are used to describe the pattern of relationship between variables (Frankfort-Nachmias & Nachmias, 2008). The components of manipulation and control which are present in true experimental studies are thus lacking in a cross-sectional study design (Frankfort-Nachmias & Nachmias, 2008).

I conducted the study in a single site hence all information collected was limited to the patient cohort from a single HIV center. Generalizability of findings may be questionable. However, the hospital is the largest non-governmental HIV center in Mombasa County with patients from a diverse background.

Internal validity threats in cross-sectional designs include selection bias, recall bias, and information bias (LaMonte, 2013). All children aged between 5 and 15 years receiving antiretroviral therapy at the hospital were eligible for enrolment in the study. The risk of selection bias was further reduced because there was no investigator-driven allocation to either arm of the study. Nevertheless, selection bias remains the main limitation of the study because of self-selection into palliative care. There was a further risk of potential sample selection bias from participation in this study. In order to reduce the impact of selection bias, patient characteristics such as age, gender, duration on antiretroviral therapy, and CD4 count were controlled when testing RQ3.

Data were collected from the children's charts in the medical records department. There is thus a risk of inter-rater and intra-rater differences. This was addressed by training the data abstractors and then conducting a pilot study where intrarater and interrater reliability was ascertained.

In cross-sectional studies, there is a risk of incidence-prevalence bias which is a form of selection bias (Szklo & Nieto, 2014). The two important types of incidence-prevalence bias are duration ratio bias and point prevalence complement ratio bias. There could be a possibility that the duration of pain symptoms in children who opted for the palliative care components may be different from those who did not opt for palliative care component as part of comprehensive care. Because pain is an important symptom in HIV-positive children (Farrant et al., 2012; Harding et al., 2010; Harding et al., 2012, Merlin et al., 2012; Perry et al., 2013), there is a risk of duration ratio bias which may affect the internal validity of the study. Use of relative risk instead of prevalence rate ratio of pain when comparing both groups may be one way to reduce this bias.

The point prevalence complement ratio bias may occur if point prevalence of pain in both groups is used to compare the prevalence of pain. The bias is likely to occur in cases where the point prevalence is higher in those who did not opt for palliative care compared to those who received palliative care. If the point prevalence complement ratio is close to 1.0, the bias would be negligible. However, if the ratio is markedly more or markedly less than 1.0, there could be an important bias that needs to be taken into account when interpreting findings from this study.

There is a limited risk of recall bias as psychosocial and physical health scores were recorded in the chart if the symptoms were present at the time of the clinic visit. There is limited recall associated with such questions. Also, information on CD4 count was determined from the patient chart directly without getting any information from the patient.

The aim of this study was to determine whether integrating palliative care as part of comprehensive care in HIV-positive children receiving antiretroviral therapy is beneficial in reducing the symptom burden (psychosocial and physical) in children. However, there is a risk of information bias, specifically, temporal bias (Szklo & Nieto, 2014) in such study. Establishing temporal sequence is thus a challenge. It may be difficult to determine what came first, the absence or reduction of pain or the effect of palliative care. Hence, despite the presence of a statistical association, it may be difficult to establish a time sequence.

One possible method to reduce this bias would be to determine whether an association does, in fact, exist between palliative care and reduction of symptom burden. Such information can be retrieved from existing literature. Palliative care has shown benefits through reduction of the symptom burden in patients with conditions such as asthma, COPD, stroke, health failure, diabetes, and cancers (Ali et al., 2003; Bakitas et al., 2009; Brown, 1992; Fogarty et al., 1999; Forster et al., 2012; Higginson et al., 2010; Kotses et al., 1995; Miller et al., 2005; Rabow et al., 2004; Temel et al., 2010; ZuWallack et al., 2011). Few studies have also shown benefits of individual aspects of palliative care in HIV-positive adults (Green et al., 2010; Harding et al., 2010, Harding et al., 2013; Lowther et al., 2014).

A second method of addressing temporality would be to enroll children with pain and symptom burden in a prospective study and provide them with palliative care. Such children may then be evaluated for absence or reduction of the symptom burden. This may identify the proper temporal sequence and lend support to the proposed association made in the cross-sectional study.

Construct validity in this study was addressed by ensuring that physical and psychosocial burden are assessed using the PEDSQL which is a validated instrument. Reliability and validity of the PEDSQL have been tested in a number of studies (Varni et al., 1999; Varni et al., 2002; Varni et al., 2003; Varni & Limbers, 2009; Varni et al., 2010). Statistical conclusion validity in the study was addressed by ensuring there is an appropriate sample size for the chart reviews. The minimum sample size was calculated using G*Power though all children aged 5 to 15 years accessing antiretroviral treatment at the center were enrolled in the study.

Ethical Procedures

Before any charts were reviewed and information retrieved, ethical approval for the study was sought from the Walden University Institutional Review Board (IRB). The IRB approval number for this study was 07-26-16-0395061. Regulations for conducting a study in Kenya require a local IRB approval which was sought from the Ethics Review Committee in Kenya. The ERC approval number from KNH-UON-ERC was P268/03/2016. Once all approvals were in place, data collection began.

All patient charts are stored in the medical records department. Each child has a unique identifier which is recorded on the patient chart. Study numbers were assigned to each patient chart by the medical records staff. Names of patients were not revealed to me. The study numbers of eligible patients and the relevant information were extracted from the patient chart. All information was thus de-identified from the patient and is not be traceable to the individual patient.

The information collected was at a single point in time. There was no follow-up information collected. The information collected was entered into an Excel sheet and the chart returned to the medical records department. No additional information was retrieved from the chart. There was no direct communication with the children or their guardians.

All information collected was stored in an Excel/SPSS worksheet, and will be destroyed after a period of 5 years.

Summary

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. I used a quantitative research mode and extracted information from the patients' charts. Treatment outcomes of children on palliative care were compared to children on standard HIV care and treatment.

In such a design, a sample is randomly selected from the population and asked a set of questions. Hence, mostly a survey design is deployed in such studies (Frankfort-Nachmias & Nachmias, 2008). It comprises a single period of observation without any follow-up and a snapshot of the population is obtained.

I conducted chart reviews at the hospital. All pediatric patients enrolled in the HIV program aged between 5 and 15 years had their charts reviewed. The hospital provides palliative care to children with an opt-out option. Children and parents have the option of refusing to participate in the palliative care program. Hence, there is an arm that receives standard HIV care and treatment and there is an arm that receives palliative care in addition to standard HIV care at the center.

The following variables were of interest in the study and were obtained from the chart: date of birth, gender, date of start on antiretroviral therapy, nadir CD4 count (prior to provision of palliative care), most recent CD4 count, type of care, psychosocial and physical health scores. A model of logistic regression was created to determine whether there is a difference in physical and psychosocial health summary scores between the two groups controlling for age, gender, duration of antiretroviral therapy, and CD4 count between each group. Chapter 4 will include data collection and results of the study.

Chapter 4: Results

Introduction

Children living with HIV/AIDS continue to face symptom burden despite being initiated on antiretroviral therapy (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). This affects treatment outcomes (Harding et al., 2006, Lowther et al., 2014). Such needs can be addressed through palliative care. The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. I conducted a chart review of children who were initiated on palliative care and compared the health outcomes to those children who received standard HIV care and treatment but without palliative care. This chapter will include details on data collection, analysis, and presentation of results of the study.

Pilot Study

I conducted a pilot study prior to the initiation of data collection proper. In the pilot study, charts for children receiving palliative care and those receiving standard care were randomly assigned for data extraction. Ten charts were randomly selected for the pilot. I recorded the data in an Excel spreadsheet. Interrater reliability was tested by asking at least two data abstractors to abstract data from the same chart. There was no difference in the data extracted by the two data abstractors (Cohen’s kappa agreement > 0.90; Pennsylvania State University, 2016). Intrarater reliability was tested by getting a data abstractor to abstract data from the same chart on two different occasions. Again, the data abstracted on both occasions were the same (Cohen's kappa agreement > 0.90). The pilot study showed that data collection from the charts of patients would be a fairly simple exercise as all information was directly available in the chart. The pilot study had no impact on the main study, and there were no changes required in data analysis strategy.

Data Collection

At the time of the study, 949 children were receiving antiretroviral therapy at the center. Figure 2 shows the delineation of children on antiretroviral therapy eligible for the study. Based on the eligibility criteria, 277 children were eligible for the study. Of these, 180 had received standard care and 97 had received palliative care. Based on the sample size calculation, a minimum of 86 children was required in each arm. However, as proposed, all eligible charts were included in the analysis.

I conducted data collection from August 1st, 2016 to August 31st, 2016. The charts were available at the medical records department of the center from where they were retrieved and the following variables were extracted and filled in an Excel spreadsheet: date of birth, gender, date of initiation of antiretroviral therapy, type of care, nadir CD4, last CD4, emotional functioning score, school functioning score, social functioning score, psychosocial summary score, and physical health summary score. The data were then exported to SPSS (Version 21) for analysis. There were no discrepancies in data collection from the plan.

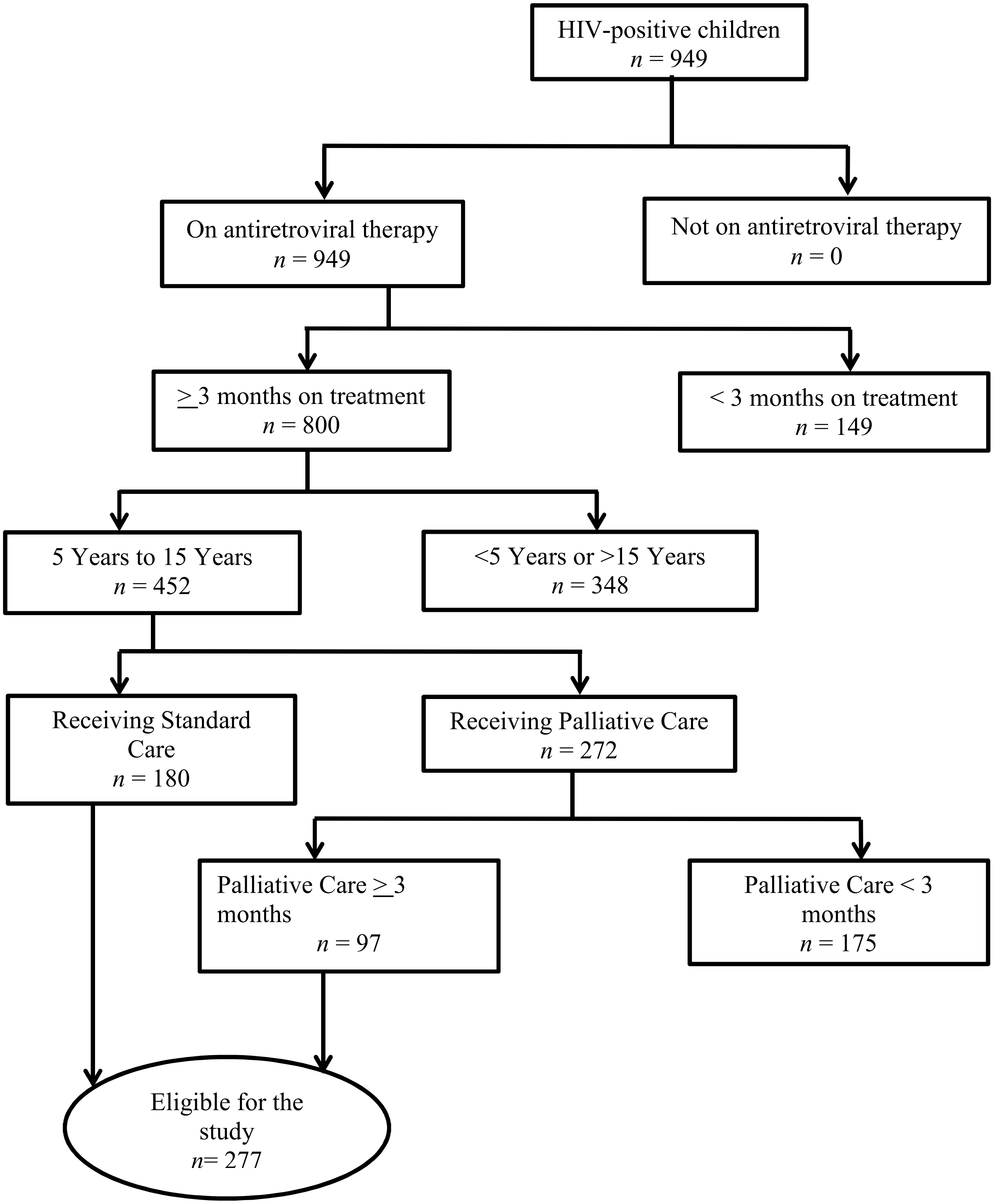
HIV-positive children
n = 949
On antiretroviral therapy
n = 949
Not on antiretroviral therapy
n = 0
≥ 3 months on treatment
n = 800
< 3 months on treatment
n = 149
5 Years to 15 Years
n = 452
<5 Years or >15 Years
n = 348
Receiving Standard Care
n = 180
Receiving Palliative Care
n = 272
Palliative Care ≥ 3 months
n = 97
Palliative Care < 3 months
n = 175
Eligible for the study
n= 277

Figure 2. Flowchart showing the delineation of children on antiretroviral therapy eligible for the study.

Descriptive and Demographic Characteristics

A total of 277 charts were eligible for review and I extracted data from these charts. Forty-eight percent (*n* = 134) of the children were female. The mean age of all children was 11.6 (*SD* = 3.19). The mean duration on antiretroviral therapy was 73 months (*SD* = 35.64). Thirty-five percent (*n* = 97) of the children had received palliative care in the last 3 months. Mean nadir CD4 was 847.1 (*SD* = 506.01) and the mean last CD4 for all children was 840 (*SD* = 541.25).

Characteristics by Type of Care

Standard Care

One hundred and eighty children (65%) of all children had received standard HIV care and treatment in the last 3 months. Forty-five percent (*n* = 81) of children who received standard care were female, and the mean age was 12 years (*SD* = 3.26). The mean duration on antiretroviral therapy of this group was 79.2 months (*SD* = 34.586). Mean nadir CD4 was 798.43 (*SD* = 487.03) and the mean last CD4 was 784.665 (*SD* = 543.6355).

Palliative Care

Ninety seven (35%) of all children had received standard HIV care and treatment in the last 3 months. Fifty four point six percent (*n* = 53) of children who received standard care were female, and the mean age was 10.823 years (*SD* = 2.87). The mean duration on antiretroviral therapy of this group was 63.2 months (*SD* = 35.41). Mean nadir CD4 was 935.1 (*SD* = 529.97) and the mean last CD4 was 946.398 (*SD* = 523.38).

Assumptions of Normality

Prior to analysis, I evaluated the data according to tests for normality. Q-Q plots were derived, and further statistical methods such as Kolmogorov-Smirnov and Shapiro-Wilk were applied to the variables to check for normality. Results of the normality tests are shown in Table 4. Normal Q-Q plots and observed values of each variable are shown in the appendix.

Table 4

Table Showing Results of Tests of Normality

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	*df*	*p* value	Statistic	*df*	*p* value
Age	.158	259	.000	.888	259	.000
Duration	.092	259	.000	.974	259	.000
NadirCD4	.087	259	.000	.953	259	.000
LastCD4	.093	259	.000	.930	259	.000

Note. a. Lilliefors Significance Correction

The Kolmogorov-Smirnov and Shapiro-Wilk tests for normality revealed *p* values of .0 for each variable. The *p* value of .0 (< .05) demonstrated that the data significantly deviates from a normal distribution. Thus, the assumptions of the independent *t* test and linear regression were not met. I used a Mann-Whitney Test as a nonparametric test instead of the independent *t* test and logistic regression instead of linear regression.

Results

In the following subsections, I will present the results based on the RQs.

Research Question 1 (RQ1)

RQ1 was: Is there a significant difference in psychosocial health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only? The first variable analyzed under psychosocial health was emotional functioning, and the related hypotheses were:

$H_0$1a: There is no significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1a: There is a significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only

The results of the statistical analysis are shown in Table 5 and Table 6.

Table 5

The Ranks Table for Emotional Functioning

	Ranks			
	Type of Care	*N*	Mean Rank	Sum of Ranks
Emotional Functioning	Standard Care	180	123.7	22265.5
	Palliative Care	97	167.4	16237.5
	Total	277		

Table 5 shows that the mean rank for emotional functioning was higher (167.4) for children receiving palliative care compared to those receiving standard HIV care (123.4).

Table 6

Results for Mann-Whitney U Test for Emotional Functioning

Test Statistics[a]	
	EmoMS
Mann-Whitney U	5975.500
Wilcoxon W	22265.500
Z	-4.931
p value	.000

*Note.*a. Grouping Variable: Type of Care

As Table 6 shows, emotional functioning was significantly higher in the children receiving palliative care compared to those who received only standard HIV care and treatment ($U = 5975.5$, $p = .00$). So I rejected the null hypothesis and accepted the alternate hypothesis that there is a significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

The next variable I studied under psychosocial health was social functioning. The related hypotheses were:

$H_0$1b: There is no significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

H_A1b: There is a significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

The results of the statistical analysis are shown in Table 7 and Table 8.

Table 7

The Ranks Table for Social Functioning

Ranks				
	Type of Care	*N*	Mean Rank	Sum of Ranks
Social Functioning	Standard Care	180	133.17	23970.5
	Palliative Care	97	149.82	14532.5
	Total	277		

Table 7 shows that the mean rank for social functioning was higher (149.82) for children receiving palliative care compared to those receiving standard HIV care (133.17).

Table 8

Mann-Whitney U Test for Social Functioning

Test Statistics[a]	
	SocMS
Mann-Whitney U	7680.500
Wilcoxon W	23970.500
Z	-2.464
p value	.014

Note. a. Grouping Variable: Type of Care

As Table 8 shows, social functioning was significantly higher in the children receiving palliative care compared to those who received only standard HIV care and treatment ($U = 7680.5$, $p = .014$). So I rejected the null hypothesis and accepted the alternate hypothesis that there is a significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

The final variable studied under psychosocial health was school functioning. The related hypotheses were:

> $H_0$1c: There is no significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.
>
> H_A1c: There is a significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

The results of the statistical analysis are shown in Table 9 and Table 10.

Table 9

The Ranks Table for School Functioning

Ranks				
	Type of Care	*N*	Mean Rank	Sum of Ranks
School Functioning	Standard Care	180	120.13	21623.0
	Palliative Care	97	174.02	16880.0
	Total	277		

Table 9 shows that the mean rank for school functioning was higher (174.02) for children receiving palliative care compared to those receiving standard HIV care (120.13).

Table 10

Mann-Whitney U Test for School Functioning

Test Statistics[a]

	SchMS
Mann-Whitney U	5333.000
Wilcoxon W	21623.000
Z	-5.971
p value	.000

Note. a. Grouping Variable: Type of Care

As Table 10 shows, school functioning was significantly higher in the children receiving palliative care compared to those who received only standard HIV care and treatment (U = 5333.0, p = .00). So I rejected the null hypothesis and accepted the alternate hypothesis that there is a significant difference in school functioning between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only.

Research Question 2 (RQ2)

RQ2 was: Is there a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only? The related hypotheses were:

> $H_0$2: There is no significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

*H*_A2: There is a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only.

The results of the statistical analysis are shown in Table 11 and Table 12.

Table 11

The Ranks Table for Psychosocial and Physical Health Summary Scores

Ranks				
	Type of Care	*N*	Mean Rank	Sum of Ranks
Psychosocial Health Summary Score	Standard	180	116.95	21050.50
	Palliative	97	179.92	17452.50
	Total	277		
Physical Health Summary Score	Standard	180	128.31	23096.00
	Palliative	97	158.84	15407.00
	Total	277		

Table 11 shows that the mean rank for psychosocial health summary score was higher (179.2) for children receiving palliative care compared to those receiving standard HIV care (116.95). Similarly, the physical health summary score for children receiving palliative care was higher (158.84) than those who received standard HIV care (128.31).

Table 12

Mann-Whitney U Test for Psychosocial and Physical Health Summary Score

Test Statistics[a]	Psychosocial Health Summary Score	Physical Health Summary Score
Mann-Whitney U	4760.500	6806.000
Wilcoxon W	21050.500	23096.000
Z	-6.501	-3.816
p value	.000	.000

Note. a. Grouping Variable: Type of Care

From Table 12 it can be concluded that the psychosocial health summary score and the physical health summary score were significantly higher in the children receiving palliative care compared to those who received only standard HIV care and treatment ($U = 4760.5$, $p = .00$) and ($U = 6806$, $p = .00$). So, I rejected the null hypothesis and accepted the alternate hypothesis that there is a significant difference in physical health between HIV-positive children who receive palliative care with standard HIV care and HIV-positive children who receive standard HIV care only.

Research Question 3 (RQ3)

RQ3 was: Is there a difference in psychosocial health and physical health between children on antiretroviral therapy who receive palliative care and those who do not receive palliative care when controlled for age, gender, duration on antiretroviral therapy, and CD4 count? The related hypotheses were:

> $H_0 3$: There is no significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside

antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count.

H_A3: There is a significant difference between psychosocial health and physical health between HIV-positive children receiving palliative care alongside antiretroviral treatment and HIV-positive children on antiretroviral treatment not receiving palliative care when controlling for age, gender, duration on antiretroviral therapy, and CD4 count.

In order to conduct logistic regression, the dependent variable was converted to a binary variable (high and low) based on the median score. I conducted logistic regression for physical and psychosocial health summary scores, and the results are shown in Table 13 to Table 18.

Psychosocial health.

Table 13

Model Summary for Psychosocial Health

Model Summary			
Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	305.886	.179	.239

The explained variation in the dependent variable (psychosocial health), as seen in Table 13, based on the model ranges from 17.9 to 23.9%.

Table 14

Classification Table for Psychosocial Health

Classification Table[a]					
	Observed		Predicted		
			High and low		Percentage Correct
			1.00	2.00	
Step 1	High and low	1.00	113	28	80.1
		2.00	52	66	55.9
	Overall Percentage				69.1

Note. a. The cut value is .500

Table 15

Variables in the Equation for Psychosocial Health

Variables in the Equation									
						Odds	95% C.I.for EXP(B)	
		B	S.E.	Wald	*Df*	*p* value	Ratio	Lower	Upper
Step 1[a]	Age	.200	.060	11.107	1	.001	1.222	1.086	1.375
	Gender(1)	-.315	.280	1.264	1	.261	.730	.421	1.264
	Duration	-.001	.004	.025	1	.874	.999	.991	1.008
	NadirCD4	.001	.000	2.918	1	.088	1.001	1.000	1.002
	LastCD4	-.001	.000	2.237	1	.135	.999	.998	1.000
	Palliative Care	1.854	.326	32.321	1	.000	6.387	3.370	12.104
	Constant	-4.949	1.132	19.097	1	.000	.007		

Note. a. Variable(s) entered on step 1: Age, Gender, Duration, NadirCD4, LastCD4, TypeofCareCode.

From Table 15, it can be noted that age (p = .001) added significantly to the model. However, gender (p = .261), duration on antiretroviral (p = .874), nadir CD4 (p = .088), and last CD4 (p = .135) did not add significantly to the model. Children receiving palliative care had 6.4 times higher odds (*p*=.000) of having above average psychosocial health scores.

Physical health.

Table 16

Model Summary for Physical Health

Model Summary			
Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	230.390^{a}	.259	.372

The explained variation in the dependent variable (physical health), as noted in Table 16, based on the model ranges from 25.9 to 37.2%.

Table 17

Classification Table for Physical Health

Classification Table^{a}					
	Observed		Predicted		
			High and Low		Percentage Correct
			1.00	2.00	
Step 1	High and Low	1.00	35	38	47.9
		2.00	7	179	96.2
	Overall Percentage				82.6

Note. a. The cut value is .500

Table 18

Variables in the Equation for Physical Health

Variables in the Equation									
							Odds	95% C.I.for EXP(B)	
		B	S.E.	Wald	Df	*p* value	Ratio	Lower	Upper
Step 1[a]	Age	.420	.072	34.539	1	.000	1.522	1.323	1.751
	Gender(1)	.093	.334	.077	1	.781	1.097	.570	2.112
	Duration	-.006	.006	1.158	1	.282	.994	.983	1.005
	NadirCD4	-.001	.001	3.597	1	.058	.999	.998	1.000
	LastCD4	.001	.001	3.752	1	.053	1.001	1.000	1.002
	Palliative Care	1.822	.422	18.687	1	.000	6.186	2.707	14.131
	Constant	-5.708	1.289	19.596	1	.000	.003		

Note. a. Variable(s) entered on step 1: Age, Gender, Duration, NadirCD4, LastCD4, TypeofCareCode.

From Table 18, it can be noted that age (*p* = .00) added significantly to the model. However, duration on antiretroviral therapy (*p* = .282), gender (*p* = .781), nadir CD4 (*p* = .058), and last CD4 (*p* = .053) did not add significantly to the model. Children receiving palliative care had 6.18 times higher odds (*p* =000) of having above average physical health scores.

Summary

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. The research approach was that of a quantitative mode. A chart review was conducted of children who were initiated on palliative care. Treatment outcomes were compared to those children who received standard HIV care and treatment but without palliative care.

Of the 949 children on antiretroviral therapy at the hospital, 277 were eligible for chart review. Ninety seven (35%) of these had received palliative care while the rest had received standard care for HIV treatment. The PEDSQL has two major components: the psychosocial health summary score and the physical health summary score. The psychosocial health summary score is a summation of the emotional, social, and school functioning score.

Three RQs were studied. The RQs were aimed to understand whether there was any significant difference between psychosocial health and physical health between children who received standard care compared to those who received palliative care. The third RQ was to understand whether there is a difference when controlled for age, gender, duration on antiretroviral therapy, nadir CD4, and last CD4.

The plan was to address RQ1and RQ2 using the independent *t* test and the third one using a model of linear regression. However, the assumption of normality for parametric tests was not met. Nonparametric test – Mann-Whitney test – and logistic regression were thus conducted.

Mann-Whitney test results indicated a significant difference in emotional (U = 5975.5, p = .00), social (U = 7680.5, p = .014), and school functioning (U = 5333.0, p = .00) between children receiving palliative care and those receiving standard HIV care with significantly higher scores in the palliative care group. The overall psychosocial health score was also significantly higher in children who had received palliative care (U = 4760.5, p = .00). Physical functioning was also better in children who had received palliative care compared to those who received only standard HIV care ($U = 6806$, $p = .00$). So, I rejected the null hypotheses for RQ1 and RQ2.

In the model for psychosocial health, age ($p = .001$) added significantly to the model. However, gender ($p = .261$), duration on antiretroviral ($p = .874$), nadir CD4 ($p = .088$), and last CD4 ($p = .135$) did not add significantly to the model. In the model for physical health, age ($p = .00$) added significantly to the model. However, gender ($p = .781$), duration on antiretroviral therapy ($p = .282$), nadir CD4 ($p = .058$), and last CD4 ($p = 0.53$) did not add significantly to the model. Chapter 5 will include the summary, conclusions, and recommendations emanating from this study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Children living with HIV/AIDS in sub-Saharan Africa face numerous challenges (Campos et al., 2009). Despite the roll-out of antiretroviral drugs, such children continue to present with physical and psychosocial symptoms (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). The burden of physical problems is higher in HIV-positive children compared with HIV-negative children (Harding & Sherr, 2014; Parker et al., 2014). This affects treatment outcomes and compromises the quality of life of children living with HIV/AIDS (Gonzalez et al., 2011). The emphasis of palliative care is to provide holistic patient-centered care, including the impact of illness on the family and recognition of the importance and interdependence of physical, psychosocial, social, and spiritual symptoms, alongside antiretroviral therapy (WHO, 2006).

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on treatment outcomes in HIV-positive children on antiretroviral therapy. The research approach was that of a quantitative mode. I conducted a chart review of children who were initiated on palliative care and compared treatment outcomes to those children who received standard HIV care and treatment but without palliative care. This chapter will include a summary of key findings of the study, interpretation of findings, study limitations, recommendations, implications, and conclusion.

Key Findings of the Study

The key findings of this study were: (a) there is a significant difference in emotional functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only, (b) there is a significant difference in social functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only, (c) there is a significant difference in school functioning between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only, (d) there is a significant difference in physical health between HIV-positive children who receive palliative care along with standard HIV care and HIV-positive children who receive standard HIV care only, (e) age is a contributing factor to psychosocial health in patients receiving palliative care, and (f) age is a contributing factor to physical health in patients receiving palliative care.

Interpretation of Findings

The results of this study found that emotional functioning, school functioning, and social functioning were better in children who had received palliative care for at least 3 months compared to children who had received standard HIV care in Kenya. Emotional, school, and social functioning are indicators of psychosocial health in PEDSQL (Varni et al., 1999). The PEDSQL inventory is a tool designed to assess the HRQOL in children

(Varni et al., 1999). The tool is a practical, validated, generic measure of the quality of life of children (Punpanich et al., 2010).

HRQOL was introduced into HIV/AIDS research on quality of life of patients in 1990 (Wu et al., 1990). At first, it was used to assess the impact of ART on the well-being of patients. Subsequently, it was used to report disease burden, monitor health changes, and evaluate health care programs (Hays et al., 2000). There are two important health dimensions that are tested in the PEDSQL. These are physical functioning and psychosocial functioning. Psychosocial functioning is derived from emotional functioning, social functioning, and school functioning.

The findings on participants' psychosocial well-being in this study were consistent with findings in similar studies. Psychosocial well-being has been studied in children from various angles. In the study by Xu et al. (2010), results revealed that children who had a parent living with HIV/AIDS or who had lost either parent to HIV/AIDS had a lower quality of life scores than children who did not have an HIV confirmed parent (Xu et al., 2010). The findings are also consistent with older studies where the association of self-esteem and psychosocial problems were assessed (Ravaeis et al., 1999; Sandler et al., 2003).

The findings of this study contribute to the comfort plan proposed by Henley (2002); the home-based care model that links hospital, clinics, and home care proposed by Uys (2003); the clinical and palliative day care services model proposed by Knapp et al. (2009); and the hospice initiated antiretroviral therapy model proposed by Harding et al. (2009). However, the findings of this study additionally revealed the possibility of an integrated nurse-led out-patient model for HIV-positive children. The study by Lowther et al. (2014) had similar findings for the adults' population.

One major limitation of previous studies that have conducted a needs assessment of palliative care in HIV-positive children is the use of morbidity and mortality data on children (Connor et al., 2014). This limits the definition of palliative care to end of life instead of from the time of diagnosis when it should ideally begin (Connor et al., 2014). In this study, I did not limit the definition of palliative care to end of life. This is an important strength of the study that separates from previous studies on palliative care in HIV-positive children.

The results of this study also revealed a significant difference in psychosocial health between children who had received palliative care compared to those who had not ($U = 4760.5$, $p = .00$). These findings are similar to those seen in the study by Lyon et al. (2008). In the study by Lyon et al., children who were HIV-positive and were enrolled for palliative care reported that their psychosocial health was well preserved. Children who enrolled in palliative care were those who had a low quality of life score, in general, as well as low health perception and physical and social functioning (Lyon et al., 2008). These limitations were addressed in my study, where all children regardless of their quality of life were provided an option of palliative care.

Improvements in physical and psychosocial health were also noted in this study. These findings are similar to those shown by Lowther et al. (2015) in the randomized study conducted on adults. Lowther et al. used the A-POS, the MOS-HIV, GHQ-12, and the CSRI.

When controlling for variables such as age, gender, duration on antiretroviral therapy, nadir, and last CD4, it was noted that age contributed to the model of psychosocial and physical health. An increase in age contributed to better physical and psychosocial health. Older children receiving antiretroviral therapy are more likely to have better physical and psychosocial health than younger children. One explanation would be that as the child grows older, there is more acceptance of the disease. Wiener et al. (2012) demonstrated that young adults are open to even end of life such discussion, and they take it with much interest. Older children often have a better understanding of the disease, and this may contribute to better physical and psychosocial health.

The overall findings of this study are in consonance with the tenets of the humanistic nursing theory. Amongst the tenets of the humanistic nursing theory is the building of trust in the involvement of care provided from one human being to another (Franca et al., 2013). The emotional well-being of children receiving palliative care can be explained using this tenet. Once the child has trust in the provision of care and the caregiver, the child is likely to have better emotional health.

Humanistic nursing is described as the process in which the nurse and the patient meet in a goal-oriented direction to improve well-being in the lived world (Paterson & Zdedard, 1976). The goal in palliative care is to improve physical, social, emotional, and spiritual well-being (WHO, 2006). The findings of this study are consistent with the overall construct of the humanistic nursing theory, which is to improve well-being in the lived world.

Children who had better physical and psychosocial health were those who received palliative care. Palliative care is provided by the nurses attending to the child. Nurses play an integral role in the provision of palliative care to children with chronic terminal illnesses (Lowther et al., 2015). Such provision of care involves intersubjective interaction between the nurse and the child and that is the core emphasis of the humanistic nursing theory (Paterson & Zdedard, 1976).

Limitations of the Study

I conducted the study in a single out-patient center by collecting information from the patients' charts. I did not conduct the interviews myself. The assumption was that all information collected on the PEDSQL was accurate.

The PEDSQL has a general limitation in that it is based on patient information and thus remains open to information bias (Lyon et al., 2014). The PEDSQL does not address the issue of stigma related to HIV/AIDS. HIV-related stigma is common in children and particularly in school children (Lin et al., 2010; Surkan et al., 2010). It is possible that school functioning was affected by the stigma HIV-positive children face in schools. Similarly, information on socioeconomic status is important in the field of HIV especially because of the inequalities in HIV prevalence in sub-Saharan African countries (Hajizadeh et al., 2014).

The limitations of a cross-sectional study are applicable in this study. It is difficult to establish causal relationships and directionality (Frankfort-Nachmias & Nachmias, 2008). Also, the components of manipulation and control that are present in true experimental studies are lacking in a cross-sectional study design (Frankfort-Nachmias & Nachmias, 2008).

PEDSQL is used to obtain information on psychosocial and physical well-being from children. This is generally accompanied by a parent-proxy report (Varni et al., 1999; Varni et al., 2002; Varni et al., 2003; Varni & Limbers, 2009; Varni et al., 2010). However, in this study, data were collected from pediatric charts on HRQOL in children. Parent proxy was not included in the study. Internal consistency and reliability are confirmed if the minimum reliability standard required for group comparison is exceeded (Banerjee et al., 2010). In this study, data were only obtained from children.

The role of a caregiver is important when determining treatment outcomes and HRQOL in children (Sivapalasingam et al., 2014). It is interesting to note that children living with grandparents showed better quality of life scores, particularly in psychosocial domains, compared to children living with their parents (Xu et al., 2010). This finding contradicts findings of earlier studies conducted in other countries (Joslin & Harrison, 2002; Juma et al., 2004; Ozuah, 2003). One explanation for this finding could be that after the death of parents, grandparents may take a greater interest in the well-being of the child than they would otherwise. The study by Juma et al. (2004) was conducted in Kenya and showed that children living with grandparents in that part of the world had a low quality of life. Children in sub-Saharan Africa often have to care for their sick parents or grandparents. In some instances, they even have to take up financial responsibilities for the entire family (Connor et al., 2014). This may further add to the psychosocial stress (Ritcher et al., 2009). Hence, the findings by Xu et al. (2010) may not be generalized to children in sub-Saharan Africa. Additional studies in sub-Saharan Africa are required to assess the role of caregivers when determining HRQOL in children on antiretroviral therapy.

Poor adherence to antiretroviral therapy is an additional problem in sub-Saharan Africa (Loefler, 2002). This limits the virologic and immunologic response to drug therapy. High morbidity in sub-Saharan African can partly be explained by this (Harding et al., 2014). This study did not take into account adherence to antiretroviral therapy. Further studies that incorporate this would provide a holistic picture of the role of palliative care in children.

Recommendations for Research and Practice

The purpose of this study was to fill the gap in the literature by demonstrating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. The study was conducted in Mombasa, Kenya, which is a low-income setting (WHO, 2014). The research approach was that of a quantitative mode. A chart review was conducted of children who were initiated on palliative care. The quality of life was compared to those children who received standard HIV care and treatment but without palliative care. Children who received palliative care in addition to standard care had better physical and psychosocial well-being compared to children who received only standard HIV care. The findings were statistically significant and bear a clinical significance as well for practice and implementation. Incorporating palliative care into routine HIV care may improve treatment outcomes in HIV-positive children.

Palliative care has shown benefits in patients with conditions such as asthma, COPD, stroke, health failure, diabetes, and cancers (Ali et al., 2003; Bakitas et al., 2009; Brown, 1992; Fogarty et al., 1999; Forster et al., 2012; Higginson et al., 2010; Kotses et al., 1995; Miller et al., 2005; Rabow et al., 2004; Temel et al., 2010; ZuWallack et al., 2011). Few studies have shown benefits of individual aspects of palliative care in HIV-positive adults (Green et al., 2010; Harding et al., 2010, Harding et al., 2013; Lowther et al., 2014). Models of palliative care are also limited in the literature despite comprehensive programs existing in many countries (Harding et al., 2014; Lowther et al., 2014). Such reported models have shown treatment outcomes in adults and not in children. There is a paucity of information on care models and treatment outcomes of palliative care in HIV-positive children. Findings of this study can thus be used a basis for future studies in the field of palliative care and HIV in children.

While the study provides pertinent information on the impact of palliative care in children receiving antiretroviral therapy, a longitudinal study that permits long-term follow-up of children would be important. Incorporation of parent proxy report in the use of PEDSQL would improve on reliability. Future studies may also include information of socio-economic status, the role of caregiver, and adherence to antiretroviral therapy. These may be added to the variables that need to be controlled when determining the impact of palliative care in a longitudinal study.

There is a need to educate parents and caregivers on the importance and benefits of palliative care for HIV-positive children. One of the reasons that patients may not opt for palliative care is the additional time spent at the clinic (Lowther et al., 2015).

Educating the parents to spend a few minutes for the benefit of their children may result in more parents and children opting for palliative care services. On the other hand, while nurses play an important role in the provision of palliative care, it may be important to train doctors, community health workers, and psychologists in palliative care. This would enable the entire clinical team provide palliative care to the child rather than limit the provision to nurses at an outpatient center.

Despite the cross-sectional nature of the study, findings of this study can be put to practice in HIV center offering care and treatment to children. In pediatric HIV care, the primary contact person for the child and the parent is the nurse. Hence, a nurse-led approach in providing palliative care would be appropriate. A similar model was shown to be effective in adults in sub-Saharan Africa (Lowther et al., 2014). Findings of this study can be used a basis to initiate an integrated palliative care model in children.

Social Change Implications

This research may fill a gap in understanding the impact of integrating palliative care into standard HIV care provided to children on antiretroviral therapy. Despite antiretroviral initiation, people living with HIV/AIDS continue to suffer symptoms of burden of pain and psychosocial and mental stress affecting their general well-being and adherence to antiretroviral treatment (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). In fact, people living with HIV/AIDS have a higher burden of physical problems compared to the general population (Harding et al., 2014; Harding & Sherr, 2014; Parker et al., 2014). The few studies conducted to show the effect of integrating palliative care into standard HIV care have shown promising results on treatment outcomes in adults (Green et al., 2010; Lowther et al., 2012). However, these studies did not include children. HIV-positive children in sub-Saharan Africa present with additional burden and thus empirical evidence was required to assess the impact of palliative care on health status in children (Connor et al., 2014). This study addressed this gap and provided evidence on the impact of palliative care on health status in HIV-positive children.

The findings of this study can be used as a basis for integrating palliative care into care and treatment plans for children with HIV/AIDS. Integration can begin at health facility level. Integration of palliative care with standard HIV care can be incorporated in the guidelines set at the county and even national level. Research has shown that emotional, social, and school functioning are important factors that determine treatment outcomes in children on antiretroviral therapy. Addressing them through palliative care will improve treatment outcomes, quality of life, and longevity in children.

The results of this study also lead to an understanding that palliative care is not limited to patients with cancers and those requiring end of life management. Palliative care can be applied to children living with HIV/AIDS and especially those who are on ART. Its integration within care and treatment plans improves the physical and psychosocial well-being of children thus further improving treatment outcomes in children.

An advantage of integrating palliative care into standard HIV care for children would be a reduction in the burden of care on nurses (Ritcher et al., 2009). A more compassionate approach to addressing the child’s distress can thus be used. Wu and

Volker (2011) describe the application of the humanistic theory in palliative care which can result in building partnerships between the nurses and the caregivers. The theoretical concept of this study was the humanistic nursing theory. Application of this model can result in using a compassionate approach in addressing the child's health care needs.

This study was carried out in Kenya in sub-Saharan Africa. The needs of children in this region are special and thus need special attention. Addressing such needs together with antiretroviral therapy will improve treatment outcomes in HIV-positive children and improve their quality of life and thus create a positive social change in the lives of such children.

Conclusion

HIV-positive children in sub-Saharan Africa present with physical and psychosocial symptoms despite being on antiretroviral therapy (Campos et al., 2009; Fan et al., 2011; Harding et al., 2006; Willard et al., 2009). These children further present with special needs (Campos et al., 2009). Such needs may not be addressed only with ART. HIV-positive children need to have their physical and psychosocial issues attended to, and these needs can be addressed through palliative care.

HIV-positive children on antiretroviral therapy may have better treatment outcomes if palliative care is included in the treatment model. Integrating palliative care into care and treatment models will provide a holistic treatment approach to children living with HIV/AIDS and will improve treatment outcomes. Integration of palliative care with standard HIV care can be incorporated into the guidelines set at the county and even national level. Research has shown that emotional, social, and school functioning are important factors that determine treatment outcomes in children on antiretroviral therapy. Addressing them through palliative care will thus improve treatment outcomes, quality of life, and longevity in children.

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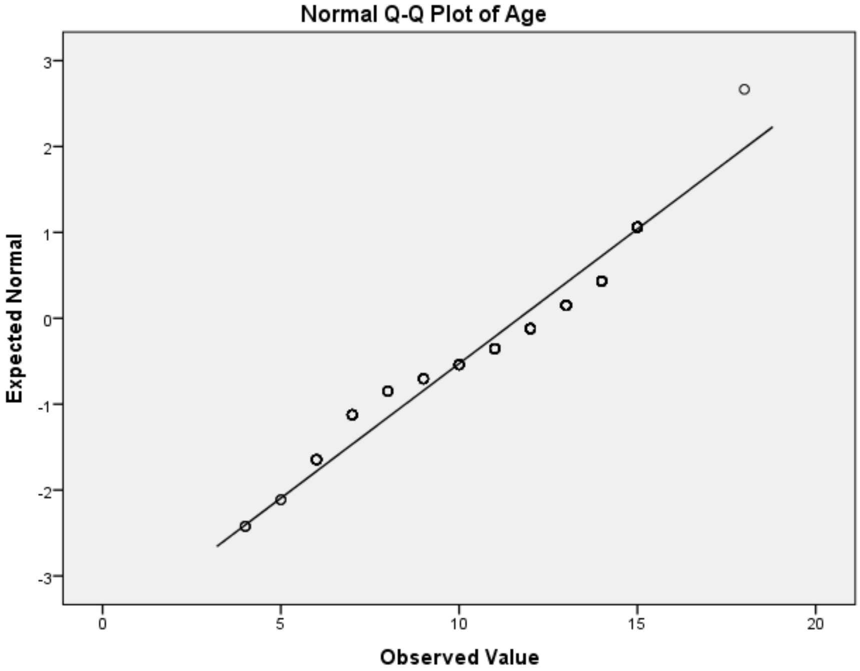
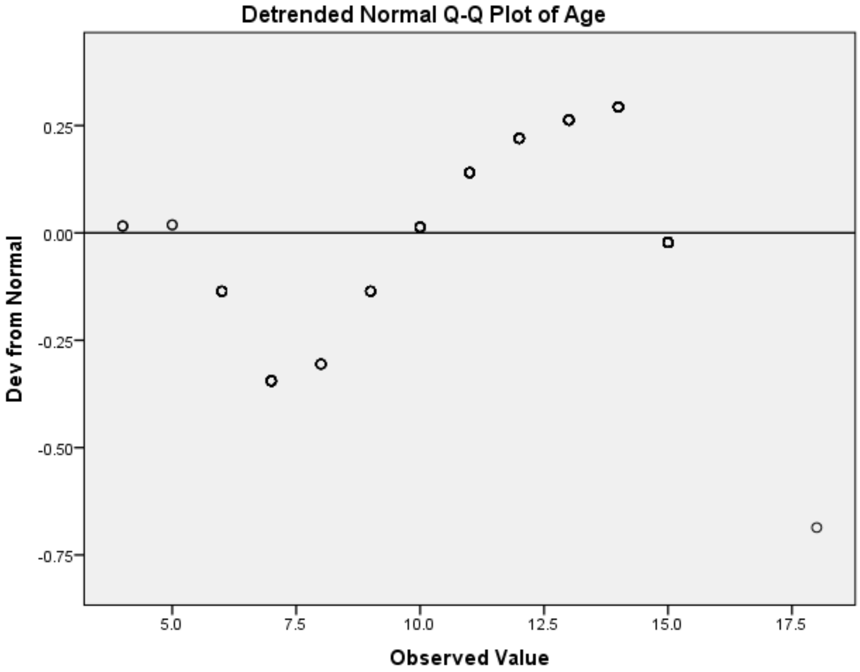
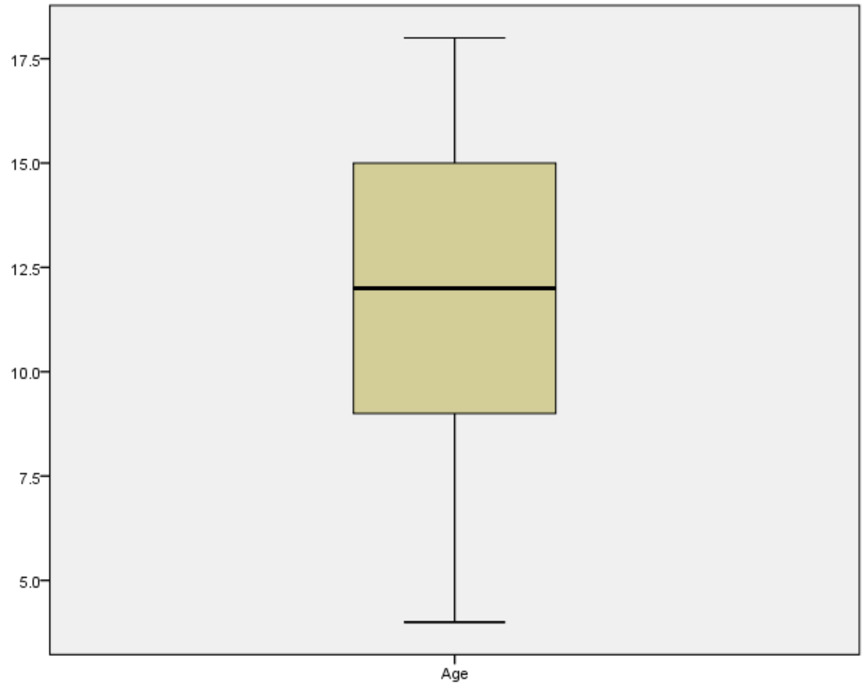
Appendix: Normal Q-Q plots and Observed Values of Each Variable

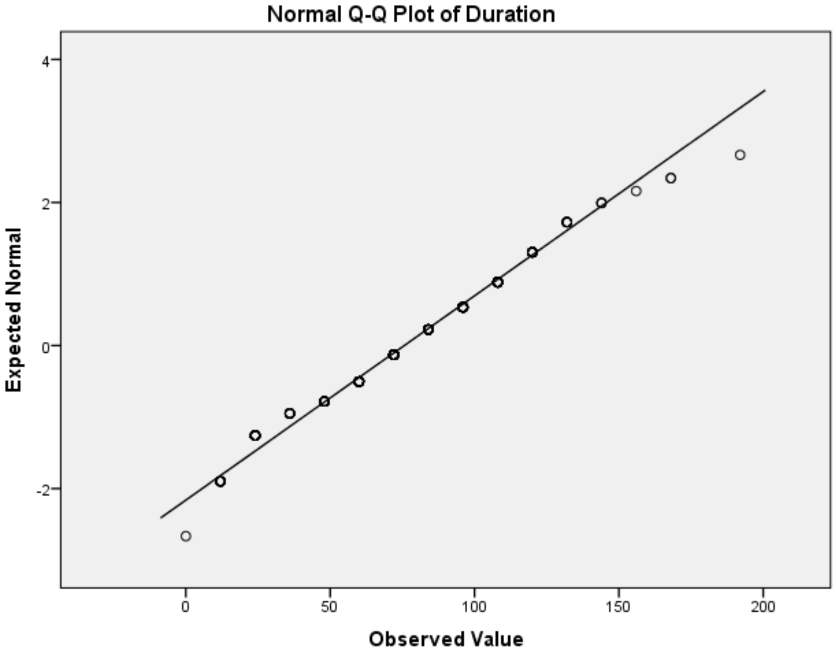
Age:

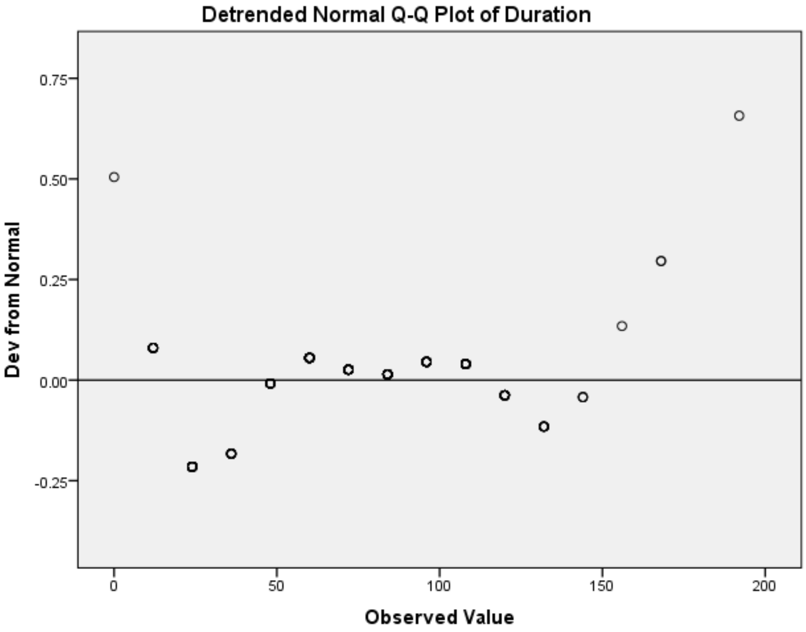


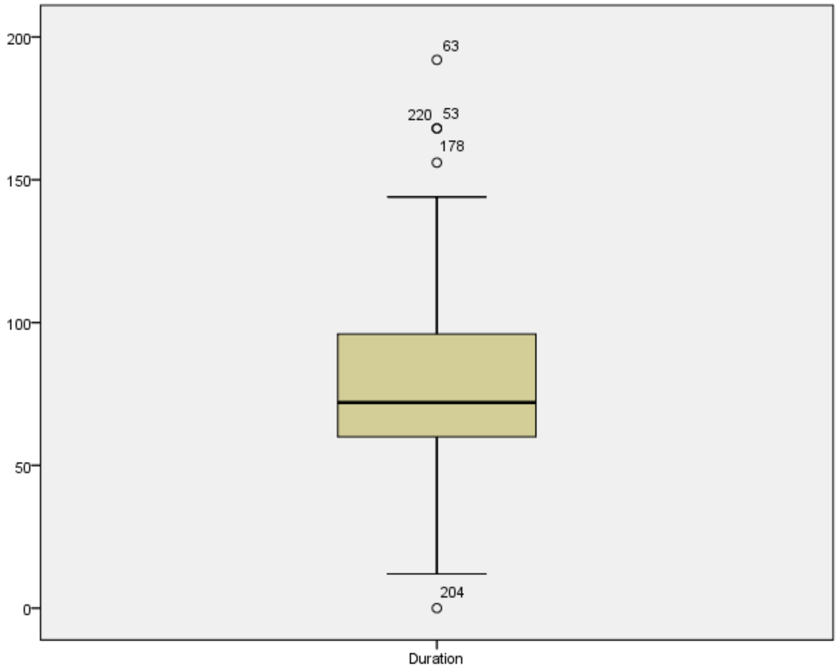




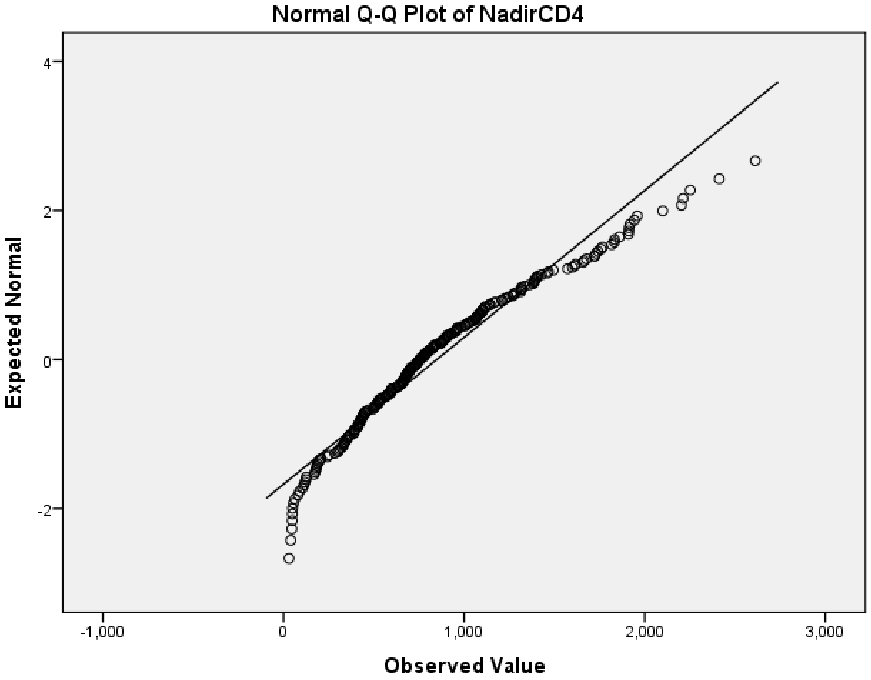
Duration on antiretroviral therapy:

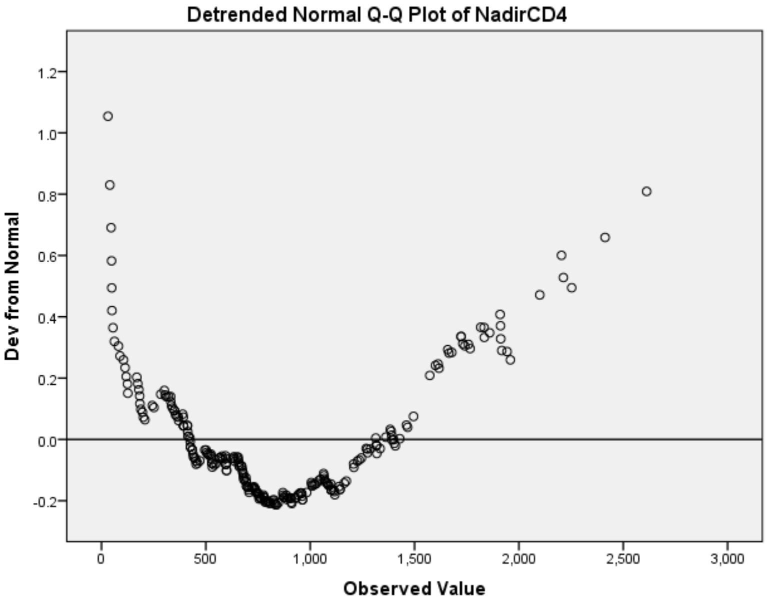

Normal Q-Q Plot of Duration
Expected Normal
4
2
0
-2
0
50
100
150
200
Observed Value

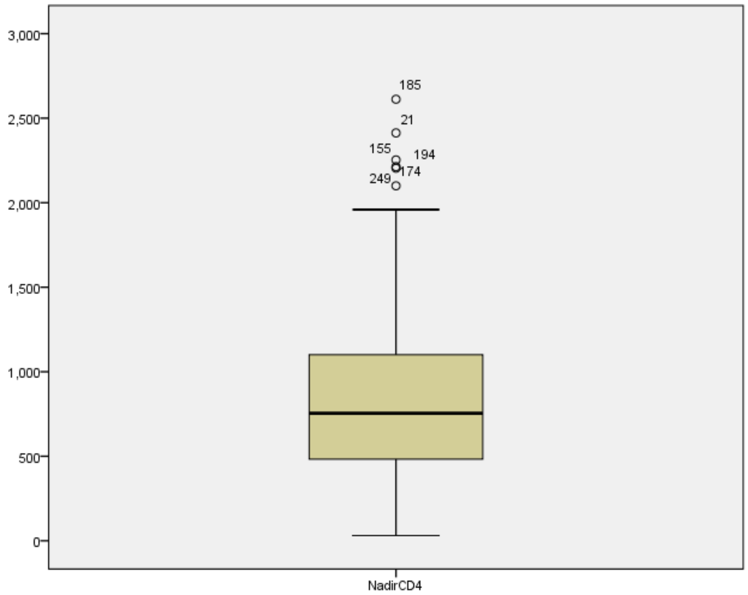

Detrended Normal Q-Q Plot of Duration
Dev from Normal
0.75
0.50
0.25
0.00
-0.25
0
50
100
150
200
Observed Value



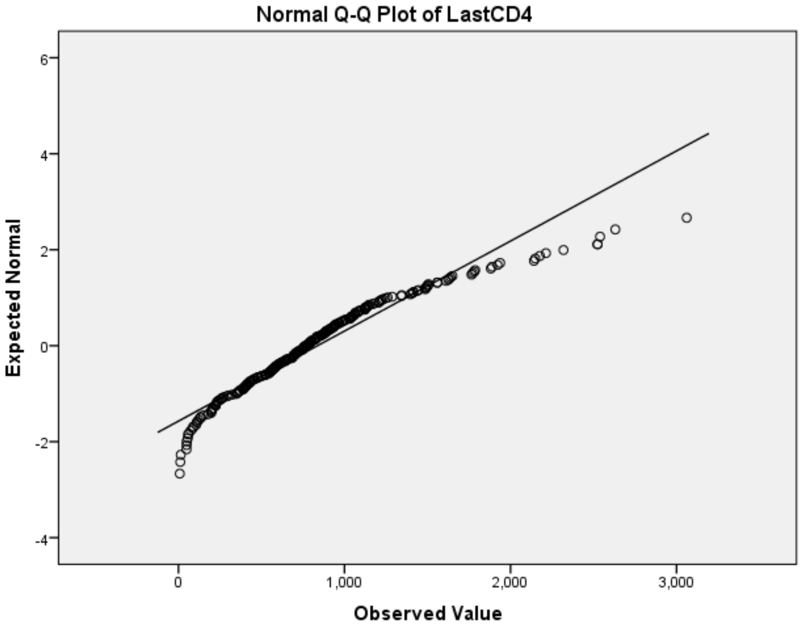
Nadir CD4:

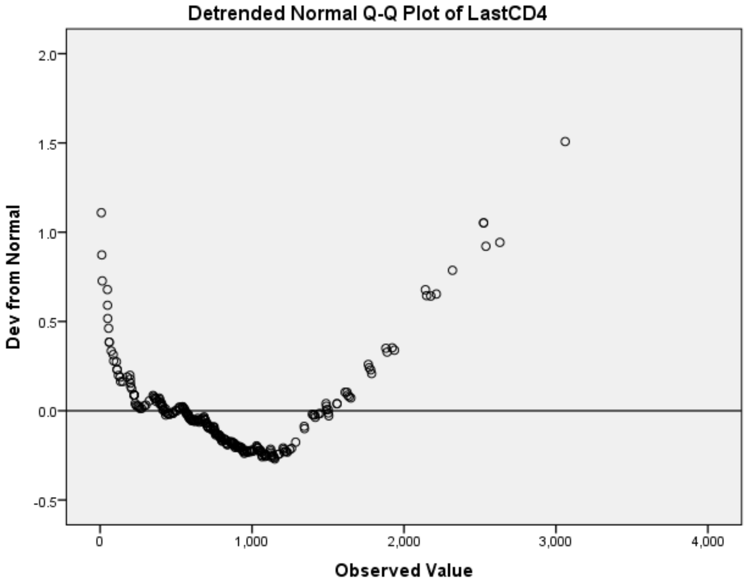

Normal Q-Q Plot of NadirCD4
Expected Normal
4
2
0
-2
-1,000
0
1,000
2,000
3,000
Observed Value

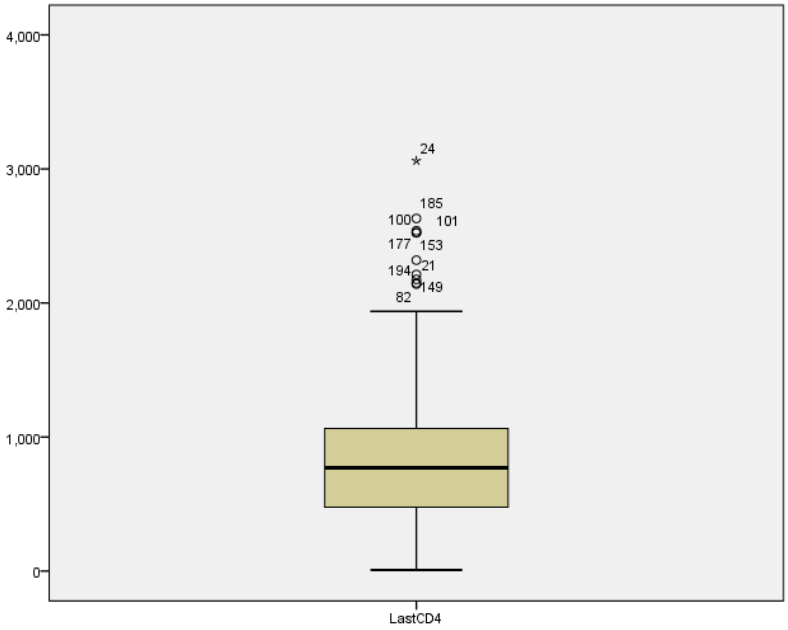

Detrended Normal Q-Q Plot of NadirCD4
Dev from Normal
1.2
1.0
0.8
0.6
0.4
0.2
0.0
-0.2
0
500
1,000
1,500
2,000
2,500
3,000
Observed Value


3,000
2,500
2,000
1,500
1,000
500
0
185
21
155
194
174
249
NadirCD4

Last CD4:


Normal Q-Q Plot of LastCD4
Expected Normal
6
4
2
0
-2
-4
0
1,000
2,000
3,000
Observed Value


Detrended Normal Q-Q Plot of LastCD4
Dev from Normal
2.0
1.5
1.0
0.5
0.0
-0.5
0
1,000
2,000
3,000
4,000
Observed Value


4,000
3,000
2,000
1,000
0
24
185
100
101
177
153
194
21
149
82
LastCD4