A DESCRIPTIVE ANALYSIS OF THE PILOT PAEDIATRIC PALLIATIVE CARE UNIT AT WITWATERSRAND HOSPICE, JOHANNESBURG

BY

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DECLARATION

I, **Danielle Catherine Lincoln** declare that this dissertation is my own work. It is being submitted for the degree of Master of Philosophy in Palliative Medicine at the University of Cape Town. It has not been submitted before for any degree or examination at this or any other University.

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SUMMARY

A study to analyze the Paediatric Palliative Care Unit at Witwatersrand Hospice, Johannesburg.

INTRODUCTION: At the beginning of the 20th century doctors were limited in what they could cure and their treatment was mainly palliation. With the advent of more sophisticated treatments and investigations, doctors moved from palliating to actively treating and curing. Problems developed when they could not cure a patient or attain remission, and patients for whom medical science could do nothing more or were dying, were given a lower medical priority. Out of this situation arose the modern hospice movement, which began at St Christopher's in London in the 1960s. Today, palliative care is seen as a basic human right for patients suffering from terminal illness. The scope for hospice care now extends to any end-stage illness, neuromuscular degenerative disease, and more recently HIV/AIDS. Paediatric palliative care is a new concept and has evolved over the past 15-20 years.

Witwatersrand Hospice, Johannesburg was started in 1975. In June 2003, Hospice Witwatersrand was approached by an organization called CHOMP (Children's Homes Outreach Medical Programmes) to admit some of the children they were managing to hospice for palliative care. CHOMP was started in 2003 in an endeavour to improve the health care of abandoned or orphaned children in the 100 Children's Homes that exist in Johannesburg, with special emphasis on those infected or affected by HIV/AIDS. A pilot paediatric palliative care unit was established at Witwatersrand Hospice.

AIM OF STUDY: to analyze the profile and management of patients admitted to the pilot paediatric unit in order to make recommendations for the further development of the unit.

OBJECTIVES:
1. Analyze the data of patients admitted in terms of :
    - demographic characteristics
    - reason for admission including diagnosis and length of stay
    - general management and treatment
    - outcome of admission which will include the outcome of the admission as well as the follow-up.
2. Identify factors that influence admission.
3. Document the management of patients in the unit.
4. Document the outcome of admission and follow-up of patients who are discharged from the unit.
5. Make recommendations for the future development of the Paediatric Palliative Care Unit at the Witwatersrand Hospice.

METHODS: The study is a retrospective, descriptive study of data collected during admissions of paediatric patients from the beginning of July 2003 to the end of June 2005. Data was collected from the files of patients admitted and recorded onto a data collection form. The information was analyzed using numerical and statistical analysis.

RESULTS: There was considerable diversity in age, diagnosis and length of admission. There was a fall off in the number of admissions in the second year of the study. HIV/AIDS was the largest group of patients admitted and there was a slightly higher prevalence of children referred from Children's Homes. The HIV+ group had a high incidence of TB and infections where common in both the HIV+ and HIV-group. Most patients were admitted for symptom control and the majority of patients required both disease-specific treatment as well as palliative treatment. Both the HIV+ and HIV- group required nutritional rehabilitation. Follow-up of patients showed that Hospice care is a point in the care rather than complete transference of care.

CONCLUSIONS: Health care workers would need a broad knowledge to cope with the diversity and complexity of disease in children admitted. Hospice would have to adopt a flexible approach to length of admission. The decrease in the admissions in the second year was likely due to anti-retroviral treatment (ART), lack of advertising and the geographical location of Wits Hospice. Transport was a problem for patients requiring hospital transfer. There was less need required for home-care follow up but there is a danger that hidden patients would be missed.

RECOMMENDATIONS: Ongoing collaboration with a paediatrician was seen to be essential as was the need to establish stronger links with hospitals and paediatric units. Active advertising and searching for patients was a priority as despite the decrease in admissions the service was seen to be have an important role in the care of children with life-threatening illness. Expansion of the unit was not seen as essential but increasing the capacity of the unit in terms of quality of care offered, transport solutions and a paediatric unit in Soweto was recommended. Ongoing support and training of staff, caregivers and relatives was necessary as well as further audits into financial viability and psychosocial and socioeconomic aspects of patients admitted.

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DEFINITIONS

Palliative care: is defined by the World Health Organization as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families." (Doyle, 1998).

Paediatric palliative care: "is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement. It is provided for children for whom curative treatment is no longer the main focus of care and may extend over many years". (ACT, 2003).

Hospice: derived from the Latin word *hospitalis* meaning friendly or the welcome to the stranger, hospices existed from medieval times for the care of pilgrims who needed rest and lodgings, or were ill and dying, as well as the care of orphans or the destitute. From 1842 several hospices were founded in France, Ireland, England and USA specifically for the care of the dying. The modern hospice movement was started in the 1960s in England by Dame Cicely Saunders focusing on quality of life until death (Doyle, 1998). In the UK, the word Hospice tends to be thought of as the building or place, whereas in USA, Hospice encompasses a multidimensional holistic philosophy of care that is independent of the place (Goldman, 2000), (Corr, 1985).

Paediatric patient: is defined as a child up to the age of 18 years.

Life-limiting or threatening conditions: those conditions for which there is no reasonable hope of cure and from which children or young people will die (ACT, 2003).

Outcome: this refers to what happened during the admission and the end result of that admission.

Disease-specific treatment: therapy that is targeted specifically to curing or actively treating a disease.

Children's Homes: this refers to institutions that care for children who have been orphaned, abandoned or whose parents and relatives are unable to take care of them.

Respite Care: care for the patient that provides an in-patient period of rest or relief from the usual situation of care, thus benefiting either the patient or caregiver or both.

CHAPTER ONE

1. BACKGROUND TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Palliative care has grown out of hospice care (Doyle, 1998). As mentioned in the definition above, Hospice care has been in existence from medieval times.

At the beginning of the 20th century doctors were limited in what they could cure and their treatment was mainly palliation. Palliative medicine is as old as medicine itself (Liben, 1996). With the advent of antibiotics, vaccination, sophisticated anaesthetic, surgical and investigative procedures, and more recently advances in genetics, immunology and molecular biology, doctors moved from palliating to actively treating and curing. Medicine became successful at improving survival rates, and in children this meant improving outcomes in cancer, congenital heart disease and prematurity. As a consequence parents and families began to think death could always be averted (Himelstein, Hilden, Boldt et al, 2004).

Problems developed when doctors could not cure a patient or attain remission, and patients for whom medical science could do nothing more or were dying were given a lower medical priority (Doyle, 1998). Dying became a symbol of failure (Liben, 1996).

Out of this situation the need for better pain and symptom control, and the addressing of fears and spiritual issues arose. This was the modern hospice movement, which began at St Christopher's in London in the 1960s. Since then hospices have grown all over the world and over the last 30 years palliative medicine has developed into a discipline that is practiced, taught, studied and researched.

Palliative care is now seen as a basic human right for patients suffering from terminal illness. The scope for hospice care now extends to any end-stage illness, neuromuscular degenerative disease, and more recently HIV/AIDS, which is perhaps the most devastating potentially life-threatening illness to affect mankind in terms of numbers affected and ease of transmission.

There are two established models of palliative care. The traditional model (Figure 1) offers palliative care when curative care fails. There is a sharp interface between curative and palliative care. The modified integrated model (Figure 2) offers palliative care from the time of diagnosis and continues throughout the course of the illness, regardless whether the patient dies. (Frager, 1997).

Figure 1 **Traditional palliative care services model (Frager, 1997)**

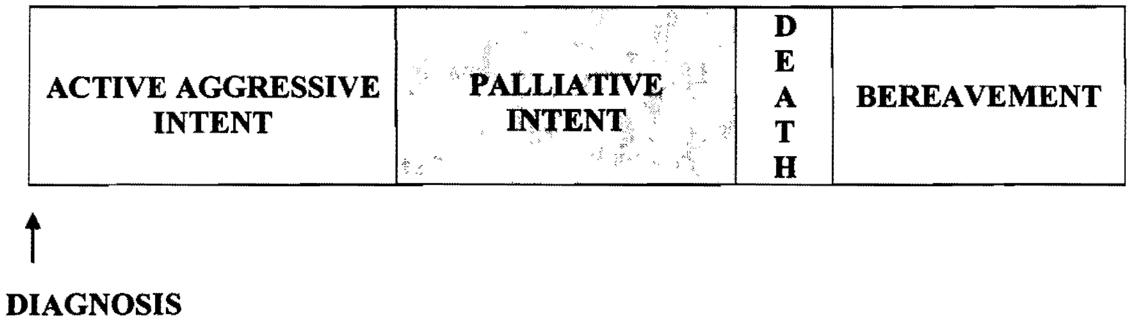
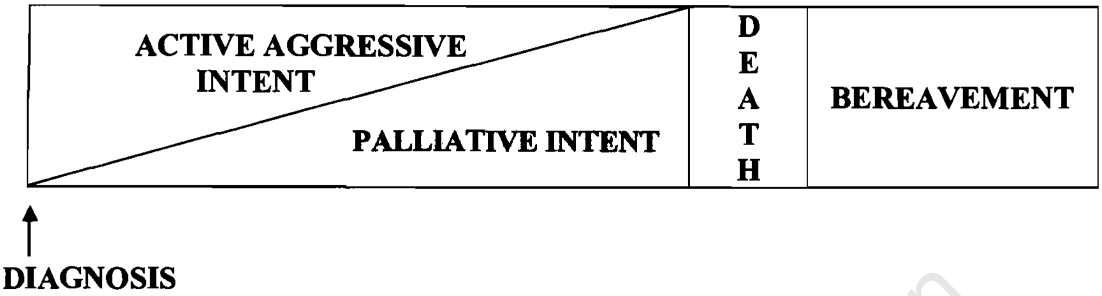


Figure 2 **Modified integrated palliative care services model (Frager, 1997)**



Paediatric palliative care is a relatively new concept and a new subspecialiality in the field of paediatric medicine internationally. Palliation for children has only evolved over the past 15-20 years (Goldman, 2000). Currently there are only 4 paediatric palliative care consultants in the UK (Hutchinson, 2003) and none in South Africa.

Witwatersrand Hospice was started in Johannesburg in 1975, and is today a large facility with a 10 bedded adult in-patient unit, a pharmacy, intake department, home-care team looking after around 200-300 patients at home, a psychosocial department, a day care facility and a Centre for Palliative Learning which is the training and education centre of Hospice, offering training to staff as well as the community. As a satellite clinic to Witwatersrand Hospice, Soweto Hospice was opened on the grounds of Mofolo Clinic in 1998 and has grown significantly since then with a current adult in-patient unit of 8 beds and a home-care department looking after 300-400 patients at home. A new, larger Hospice in Soweto is planned.

Traditionally, care offered by Witwatersrand Hospice has been for adult patients suffering from terminal illness such as cancer, HIV/AIDS, progressive neurological conditions and any disease at the end-stage, where curative options no longer exist. All the staff are trained in palliative care or if newly employed, are undergoing training.

From time to time Hospice was requested to take in paediatric patients. Paediatric palliative care was not offered as a formal service but these children were admitted and the staff applied their knowledge of adult palliative care to the children's needs.

In June 2003, Hospice Witwatersrand was approached by an organization called CHOMP (Children's Homes Outreach Medical Programme), which is a project of the Witwatersrand Paediatric HIV Working Group. CHOMP was started in 2003 in an endeavour to improve the health care of abandoned or orphaned children in the 100 Children's Homes that exist in Johannesburg, with special emphasis on those infected or affected by HIV/AIDS. The organization employs a paediatrician to look after the children. The paediatrician is assisted by volunteer paediatricians and GPs. The homes they cover vary in the number of trained and/or professional staff looking after the children. Lay people and volunteers run some of these homes. The doctors felt they needed a place to admit some of these children for palliative care. This included symptom control, respite care where clearly hospital care was inappropriate or the patient would block a much needed bed in a paediatric ward, and for procedures such as blood transfusions or dressings. CHOMP was motivated to set up this unit by the discovery of several "little hospices" within Children's Homes. Many of these homes had been faced with the need to care for terminally or chronically ill HIV-infected children. Homes had found themselves in this situation when children had been turned away from overburdened hospitals or when homes were dissatisfied at the management of children in these hospitals and had wanted to care for their dying children at the end of life.

Notwithstanding the home's good intentions, the medical care of children in these "hospices" within the Children's Homes was not always ideal. To this effect CHOMP approached Hospice Witwatersrand to establish such a unit as they felt they lacked expertise and would be duplicating services to consider a separate unit of their own.

After a number of meetings a pilot project was established. The unit was set up in a large 3-bedded adult ward that was slightly removed from the rest of the adult ward in order to maintain privacy and quiet for the adult patients. It was converted into a 5-bedded paediatric ward. Paediatrically trained nursing staff were not employed for financial reasons. The staff working in the adult unit underwent training at 2 paediatric seminars in which the following were discussed: feeding, including care of bottles and formula feeding; dehydration; nursing procedures such as oxygen therapy, nebulisation, nasogastric feeding and intravenous access; pain assessment and management in children; dyspnoea and cough in a child; and psychosocial skills required for looking after dying children. Extra nurse aides from a private agency were used when the need arose. Nurses with paediatric experience were requested.

The Hospice doctors working with adult palliative care patients looked after the paediatric patients and were assisted by the CHOMP paediatrician doing a weekly ward round.

Various meetings were held between Hospice doctors, CHOMP doctors and Hospital paediatric consultants establishing admission criteria (Appendix 6) and promotion of the unit. CHOMP doctors gave 2 lectures to paediatric hospital staff at the Johannesburg and Chris Hani Baragwanath Hospitals promoting palliative care.

From a socioeconomic point of view, the location of the unit was recognized as a problem being geographically far from many of the Children's Homes as well as Soweto, where many of the family members were living.

The paediatric unit has now reached a point where a decision needs to be made regarding the future. Clearly, the question is whether to expand the project into a more comprehensive unit that is separate from the adult unit. The researcher would like to look at various aspects of the pilot project and make recommendations. The patients admitted to the unit over the past 2 years will be analyzed. In this way recommendations for the further development of the Paediatric Unit may be established. Evaluation of a programme is critical to enhance quality and provide data to support its sustainability (Toce and Collins, 2003).

1.2 LITERATURE REVIEW

1.2.1 EPIDEMIOLOGY

"The ability of a population to benefit from an intervention depends on two things: the incidence and prevalence of a particular condition and the effectiveness of the services available to deal with it" (Field, Clark, Corner et al, 2001).

Complex, chronic conditions are defined as "any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require speciality paediatric care and probably some period of hospitalization in a tertiary care centre." (Feudtner, Christakis and Connell, 2000). There are approximately 500 000 children suffering from potentially life-threatening conditions in the USA (Himelstein et al, 2004).

There are 4 broad groups of life-limiting conditions as defined by the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), 2003:

1. Life-threatening conditions for which curative treatment may be feasible but can fail (examples: cancer, irreversible organ failure)
2. Conditions where premature death is inevitable, but have long periods of intensive treatment aimed at prolonging life (examples: cystic fibrosis, HIV/AIDS)
3. Progressive conditions without curative treatment, where treatment is exclusively palliative and may extend over years (examples: muscular dystrophy, mucopolysaccharidoses, Sickle Cell Disease, hereditary anaemias)

4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to complications and possible premature death (examples: cerebral palsy, brain and spinal cord malformations or injury)

In 2001, 25 757 children between the ages of 1-19 years died in the United States which translated to a death rate of 33.6 per 100 000 population. The Infant Mortality Rate (IMR) in the United States was 6.9 per 1000 live births in 2002. The 4 leading causes of infant deaths for 2001 were congenital malformations, disorders related to short gestation and unspecified low birth weight, sudden infant death syndrome, and newborns affected by maternal complications of pregnancy. For children aged between 1-4 years the leading causes of death were accidents, congenital malformations and cancer. Children aged from 5-9 years died most commonly from accidents, cancer, congenital malformations, homicide and heart disease. Those aged from 10-14 years died from accidents, cancer, suicide, congenital malformations and homicide. Teenagers from 15-19 years died most commonly from accidents, homicide and suicide. (Arias, MacDorman, Strobino et al, 2003).

One of the biggest concerns in Africa and certainly South Africa is the growing HIV/AIDS epidemic. In November 2004, UNAIDS released updated figures on the state of the epidemic. Globally there is an estimated 39.4 million people living with HIV/AIDS. 2004 saw 4.9 million new infections as well as 3.1 million deaths from AIDS. Although only 10% of the world's population lives in sub-Saharan Africa, it accounts for more than 60% of all people living with HIV/AIDS. This translates to an estimated 25.4 million HIV/AIDS infected people, 3.1 million new infections and 2.3 million deaths. (UNAIDS, 2003). In the same region, 60% of adults living with

HIV/AIDS are women (Galloway, 2004). This has serious implications in terms of vertical transmission of the virus.

In South Africa, HIV/AIDS is the leading cause of death accounting for 30% of all deaths for all ages (Bekker, 2003). The prevalence of HIV/AIDS is estimated to be 10.9% in a population of 46 million (just under 5 million people). Life expectancy in 2004 is 48.5 years for males and 52.7 years for females. The IMR is 55 per 1000 live births and there are 1.1 million orphans with just over 250 000 newly orphaned in 2004. (Dorrington, Bradshaw, Budlender et al, 2004). The South African under-5 IMR was estimated by the year 2000 to be 95 per 1000 (Bradshaw, Bourne and Nannan, 2003). In South Africa at the end of 2003, the age group <20 years had a prevalence of HIV of 15.8%. There were an estimated 107 548 infected babies at the end of 2004. (Department of Health Report, 2004). There were an estimated 2.5 million children (<15years) living with HIV/AIDS globally at the end of 2003. Of this 700 000 were new infections. There were 500 000 deaths of children globally in 2003. (UNAIDS, 2003). By the end of 2003, there were an estimated 14.3 million orphans aged between 0-17years in 93 countries in sub-Saharan Africa, Asia, Latin America and the Caribbean (Children on the Brink, 2004). The South African National Burden of Disease (NBD) study of 2000 estimated just over half a million deaths of children of which 106 000 were under the age of 5 years and 7800 deaths were of children between 5-14 years. This deterioration has been attributed to HIV/AIDS. In South Africa, the top 5 causes of death in children under the age of 5 are HIV/AIDS, low birth weight, diarrhoeal diseases, lower respiratory infections and protein-energy malnutrition. HIV/AIDS comprises 40.3% of deaths in this age group. In children aged between 5-9 years HIV/AIDS remains the leading cause of death closely followed by road traffic accidents. Other causes of death in this age group are fires, disease, drowning and homicide/suicide/violence. children aged between 10-14 years. Road traffic accidents and homicide/suicide/violence are responsible for 33% and 15% of deaths respectively in children aged between 10-14 years. HIV/AIDS does not feature as a cause of death in this age group although other infections such as lower respiratory infections, TB and bacterial meningitis make up a large proportion of the remaining top 10 causes. (Bradshaw et al 2003). All the top 5 diseases in the under-5 age group would benefit from palliative care.

1.2.2 NEED FOR PAEDIATRIC PALLIATIVE CARE

Franks, Salisbury, Bosaquet et al (2000), define need in epidemiological terms as 'specific indicators of disease or premature death which require intervention because the level is above that generally accepted within a particular society". The literature clearly states that palliative care for children suffering from a wide range of illnesses is an essential service (Goldman, 2000; Horsburgh, Trenholme and Huckle et al, 2002; ACT, 2003; Himelstein et al, 2004), although there is some belief that evidence supporting this need is often conflicting and of poor quality (Franks et al, 2000) . It has been estimated that between 10-20:10 000 children will require palliative care for a life-limiting condition (Hain, 2004), although there is much debate around the prevalence and requirement for palliative care due to inconsistencies in the recording of statistics (Horrocks, Somerset and Salisbury, 2002a).

It is important to stress that palliative care is appropriate for conditions when cure remains an option (Himelstein et al, 2004), and this will greatly increase the numbers in need of care.

In terms of hospice care for children, the international experience shows the majority of admissions are for children with a long-lasting, progressive and life-limiting condition, where the need for admission is largely for respite (Doyle, 1998).

There is a strong appeal to improve information on prevalence and morbidity (ACT, 2003; Horrocks et al, 2002a), as it is difficult to predict the need for services as accurate information is lacking.

1.2.3 THE CURRENT SITUATION INTERNATIONALLY

In the UK, the Children's Hospice Movement began in Oxford in the early 1980s. The first children's hospice, Helen House was opened in 1982, providing respite and terminal care for children. There are currently 27 children's hospices in the UK with 10 more being developed. In addition, there are several models of community care using multi-disciplinary palliative care teams offering comprehensive home-care support to the children and their families. (Doyle, 1998; ACT, 2003). There are currently more than 40 specialist paediatric oncology outreach workers (Farrell and Sutherland, 1998). The development of the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and their coming together with the Royal College of Paediatrics and Child Health (RCPCH) in 1995, led to the development of guidelines for the development of Paediatric Palliative Care (ACT, 2003).

Early efforts in developing paediatric palliative care in the USA were started in the late 70s and were directed at children in their own homes. Children's Hospice International (CHI) was started in 1984 to determine the accessibility of hospice care to children at which time it was established that 18% of the hospices in the USA admitted children. (Davies, 1996). Two facilities were established: an inpatient unit within St Mary's Hospital in New York and Edmarc, and a respite facility in Virginia (Davies, 1996). Since then there has been considerable growth in the paediatric hospice programme and in 1991 a consultative service on paediatric hospice programmes, Kaleidoscope Kids was established. Today there are a number of designated hospice units, but it is more common that all hospitals adopt a hospice approach to seriously ill children and their families. (Doyle, 1998).

There are both informal as well as structured palliative care programmes existing in oncology centres and children's hospitals in Canada. Canuck Place was opened in 1995 in Vancouver and was the first free-standing children's hospice in North America, offering respite, palliative care and bereavement support. Many children live in isolated, rural areas and much work has been done to establish palliative care teams within the communities. (Davies, 1996; Doyle, 1998).

In Australia the move toward paediatric palliative care is more recent and more hospital based. Childhood malignancy is the second commonest cause of death after accidents, and most of these children are looked after by the hospital oncology departments. The hospitals have a wide range of community-based support services although home-visits for children living far away are often not possible. Few palliative care services exist for children with other life-limiting diseases. Australia's first dedicated children's hospice, Very Special Kids House, was opened in Melbourne in 1996 and Bear Cottage in Sydney opened in 1998. (Doyle, 1998).

1.2.4 DEVELOPMENT OF PAEDIATRIC PALLIATIVE CARE IN SOUTH AFRICA

Like the USA, Canada and Australia, most of the care of children with life-limiting diseases in South Africa, has been at hospital level in the paediatric clinics and oncology centres. The HIV/AIDS epidemic has resulted in a number of Children's Homes opening and admitting children both infected with and affected by AIDS. Meiring (2005) shows that 20% of children in homes in greater Johannesburg are HIV infected and 31.7% are HIV affected.

In Johannesburg, Cotlands Children's Home was opened in 1936 and the Cotlands Hospice in 1996 and has been the traditional referral for children infected and affected with HIV/AIDS, chronic diseases as well as orphaned and abandoned children.

Cotlands has also recently opened a 26-bedded facility in Somerset West in the Western Cape. The unit functions mainly as a Hospice, but also as a place of safety.

Bloemfontein Hospice opened Sunflower Hospice (aka St Nicholas Hospice) in the last few years and runs an inpatient unit, which is on the grounds of and closely affiliated to a large government hospital. It also runs a comprehensive daycare programme servicing around 700 children affected by AIDS. It does not have a well-established home-care programme (this information is based on a personal visit to Sunflower Hospice in 2003).

South Coast Hospice in Kwazulu-Natal is an adult hospice that has expanded its admission criteria to children mostly infected with HIV/AIDS requiring symptom control, respite care and terminal care. South Coast Hospice works closely with the regional state hospital (this information is based on correspondence with the director of South Coast Hospice, Sr Kath Defillipi).

Kalafong Hospital in Pretoria has a 10-bedded hospice for children with life-threatening illnesses.

At present there is no formal training or qualification in paediatric palliative care for paediatricians in South Africa, although there are some paediatricians and paediatric oncologists who have an interest in palliative care and have some training in aspects of palliative care.

1.2.5 PLANNING PAEDIATRIC PALLIATIVE CARE

There is general agreement that models of palliative care need to be standardized and that everyone should have access to these services (Frager, 1997; AAP, 2000).

Palliative care must be available not only to children who are imminently dying, but also to those living with chronic, potentially life-threatening conditions (Toce et al, 2003).

A multidisciplinary team approach is recommended with emphasis on recognition of the need for palliative care and timing of palliative intervention, assessment of needs of the child and family in terms of physical, spiritual and psychosocial issues, looking into practical issues and facilitating advance care planning (Frager, 1997; AAP, 2000; Himelstein et al, 2004). It is recommended that a keyworker is identified to coordinate care of these children to prevent fragmented care. This role could be a GP or a nurse practitioner (ACT, 2003; Himelstein, 2004). The clergy were seen as helpful members of the palliative team in a study by Meyer et al 2002 in Levetown (2002).

There is much support in the literature for an integrated model of palliative care (figure 2) to be offered at diagnosis and to continue throughout the course of the illness (AAP 2000; Wolfe, 2000), however the transition from curative to palliative care lacks a comprehensive, coordinated and evidence-based approach (Contro, Larson, Scofield et al, 2002).

The success of the integrated model of palliative care (figure 2) is dependant on collaboration between all groups or individuals providing care for the child (Farrell et al, 1998; AAP, 2000; Chaffee, 2001; Horsburgh et al, 2002). Goldman, (1998) feels the need for palliative care is not clear cut. Some need it from infancy and for many years and others need it for shorter periods of time and when they are older. She goes on to say that the transition between curative treatments and palliative care is also not clear. Kane, Barber, Jordan et al (2000), feel that the introduction of palliative care early in the course of the disease is essential, providing children and families with the best of both: active therapy as well as the nurturing and support of palliative care.

There needs to be widespread recognition of the services as well as funding support by both the government (Frager, 1997) and the medical aids and private sector (AAP, 2000).

There is a danger however, in allowing unstructured and uncoordinated proliferation of palliative services under different administrations which leads to confusion for the family (Woolley, Stein, Forrest et al, 1991). Fragmentation of services leads to less effective care (Farrell et al, 1998). Co-ordination of services is essential (Doyle, 1998).

Davies (1996) feels there is no one right way to develop a children's hospice programme and the design of the programme will be dependant on the needs and resources of each situation. The location of the palliative programme is important as the service should be easily accessible to families (Doyle, 1998).

It is not possible for all health-care service providers to provide a comprehensive paediatric palliative care programme and it is unnecessary to provide more than the community needs. Corr and Corr (1985) feel the emphasis should be on providing quality of life and care rather than where an inpatient facility should be. They feel that an inpatient unit could be anywhere: a paediatric medical centre or clinic, a general hospital, a specialized paediatric hospital or a designated hospice unit. Most countries seem to be taking the route of separate hospice facilities for children who are either terminally or chronically ill and are admitted for respite care, symptom control, support for families and bereavement work, as well as outreach community programmes to facilitate home care (Corr, 1985; Goldman, 2000). These programmes can be co-ordinated by hospices, oncology units, general or paediatric units, general practitioners or community nursing services (Goldman, 2000). Respite care and bereavement care are seen as essential components of paediatric palliative care (Corr, 1985; Liben and Goldman, 1998; Horsburgh et al, 2002). Home is regarded as the best place of care for a child with a life-threatening disease (Goldman, Beardsmore and Hunt, 1990; Horsburgh, 2002). However this places great stress on the family which explains why respite care becomes an essential service giving families a break from the responsibility of caring for their child. Respite care may be for long or short breaks and needs to be available for planned as well as emergency respite (Davies, 1996; Horsburgh et al, 2002).

The literature stresses the importance that paediatric palliative care needs to be flexible, diligent and pay careful attention to the needs of patient and family to achieve quality of life for that child (Corr, 1985; Horsburgh, 2002; ACT, 2003). In a study by Stein, Forrest, Woolley et al (1989), evaluating Helen House, families made note of the importance of being made to feel special, that they were particularly supported at the time of death with the flexibility of the hospice, the experience of the staff and certain rituals being performed at the time of death that were helpful. Children have a wide range of needs and to provide a comprehensive service, needs such as education, recreation and affection need to be addressed as much as treatment and symptom control. Paediatric palliative care does not just support the child but the family as well, both nuclear and extended (Gold, 1997).

The issue of which child and when to refer the child for palliative care is generally felt to be unclear, but it should not be reserved for end-of life care only (Oleske and Czarniecki, 1999; AAP, 2000). Doctors need training in recognizing when to refer a child for palliative care (Charlton, 1996).

It is important to stress that palliative care does not mean the withdrawal of 'active' or disease specific treatment. Some active treatments are the best palliative treatments. Each treatment or intervention is weighed up according to the benefits versus the burdens for that child and a decision reached thereafter (Hutchinson, King and Hain, 2003). Palliative care must allow the child's usual doctor to maintain an ongoing role in the child's care (AAP, 2000).

Staff support in terms of supervision and training is important in order to deliver an effective service and prevent stress and burnout (Corr, 1985; Overton, 2001)). Ongoing communication skills are important as they underpin good palliative care (Charlton, 1996).

Liben and Goldman (1998) felt that a good starting point for developing paediatric palliative services is to designate a specific paediatric health care professional to coordinate the planning.

1.2.6 OBSTACLES AND BARRIERS TO PAEDIATRIC PALLIATIVE CARE

The death of a child remains one of the hardest and most stressful experiences families and health care providers have to accept (Gary, 1992; Himelstein et al, 2004). Many more adults die per year (around 2.3 million in USA) (Himelstein et al, 2004) and therefore adult palliative care has grown rapidly. Deaths of children are still regarded as unfair (Sheldon and Speck, 2002) and there is still widespread belief that death is a failure rather than a natural event (Galloway, 2004). Paediatricians in particular, see the death of a child as a personal failure (Papadatou, 1997; Khaneja and Milrod, 1998). Palliative care is often seen as giving up on the child and parents find it difficult to choose non-intervention for their child (Frager, 1997; Morgan and Murphy, 2000). There is a myth that palliative care means second best care or "passive" care as opposed to an "active" cure-directed approach and this remains a profound barrier to palliative care (Papadatou, 1997; Morgan et al, 2000). It is important that both families and professionals learn that incurable does not mean untreatable (Gary, 1992).

One of the difficulties is the diversity within the paediatric group of patients. Paediatrics encompasses a wide range of ages and developmental stages and paediatric palliative care workers need to be able to provide the care to suit these differences (Corr, 1985). Despite there being less children dying than adults, the complexity and diversity of illness is far greater (Corr, 1985) and the conditions are often rare and can last for many years (Goldman, 2001; Horsburgh, 2002). Thus paediatric health care workers need a wide base of knowledge when dealing with children and their families (Corr, 1985), as one of the requirements families need is information. The families themselves create diversity and difficulties can arise when families have to make decisions for the child (Corr, 1985).

Difficulties in identifying children who need palliative care can result in children receiving palliative care late in the dying process or not at all (Toce et al, 2003). Establishing a prognosis for children with complex diseases is very difficult for doctors (Levetown 2002; Himelstein et al, 2004). If palliative care is not readily available in the hospital teams, this may delay the transition from curative to palliative or terminal care. Other barriers are the difficulties in evaluating symptoms such as pain in small children as well as the myths that exist around children's perceptions of pain and the use of opioids (Levetown, 1996; Liben, 2000). Pain and symptom management continue to cause anxiety for professionals (Lauer, 1997).

The medical profession itself can be negative about hospice care and there remains a reluctance to acknowledge and use hospice (Gates, 1992). Doctors want to be in control of their patients and may not want them to be referred to a hospice or palliative care team (Goldman, 2000). It is important that hospices and palliative care teams are not seen as owning paediatric palliative care but rather advocating an approach to care (Corr, 1985).

For advanced countries, issues of sustainability and regulation of paediatric hospices are now becoming more of an issue rather than the struggle to start such units (Sheldon et al, 2002). The high cost of running a children's hospice remains an issue. Overton (2001), estimated that running a 10-bedded respite facility in England will cost the equivalent of R11 million a year. Costs tend to be underestimated and hidden costs are significant (Lauer, 1997). Small hospices are not cost effective (McQuillan and Finlay, 1996).

The literature indicates that ethnic minority groups and lower socioeconomic groups are less likely to use hospice care as well as having less choice of services available to them. Those who can afford extra support are more likely to access support. (Horsburgh et al, 2002). In a study by Contro et al (2002), which looked at family perspectives on the quality of paediatric palliative care, the authors found that language and cultural differences acted as a severe barrier to effective palliation.

Paediatricians are ill-equipped to deal with their patients dying (Charlton, 1996; Khaneja et al, 1998). Teaching in medical schools is fragmented with a few lectures in the first few years and clinical work generally only forming part of elective programmes (Khaneja et al, 1998). Integrated education needs to be looked into as well as programmes to help professionals cope with the loss, at both under- and post- graduate level. The professional needs to adapt cognitively, emotionally and philosophically when working with children with life-threatening diseases (Gary, 1992). In addition to the emotional aspect, paediatricians need training in palliative care (AAP, 2000). There is a lack of standards for paediatric palliative care and this is becoming a worldwide priority (Hain, 2005).

1.2.7 ADULT PALLIATIVE UNITS OFFERING PAEDIATRIC PALLIATIVE CARE

There are few hospices that are designed specifically for children (Oleske et al, 1999). Adult hospices admitting paediatric patients are a source of concern (ACT, 2003) and are rarely appropriate for children (Hain, 2002). Children should not be regarded as small adults and their needs are complex. Symptom control of children is very specialized and requires specialized knowledge and training (Papadatou, 1997; Horsburgh et al, 2000; Morgan et al, 2000). Paediatric palliative care must develop from those who are trained to care for children. Lack of paediatrically trained palliative care staff deprives children of the benefits of palliative care (AAP, 2000). Hain (2004) feels that children should have as much access to palliative medicine as adults do but that paediatricians should be furthering this cause and not adult palliative care doctors

Finlay (1995) however, feels that an adult palliative care team has a role to play in caring for children as long as they work with a paediatric team and Hutchinson et al (2003), states that a lot can be learned from the knowledge and experience of adult palliative care doctors. In addition, small hospices are expensive and it may be more cost effective to involve already established adult palliative care services (McQuillan et al, 1996).

It is important for paediatric hospices to be in a position to offer long-term support as unlike in adult care, children are often ill for a long period of time (Davies, 1996).

Despite there being differences between adult and paediatric patients and illnesses, the basic philosophy of hospice and palliative care remains the same: to enhance quality of life in a holistic way (Corr, 1985).

1.2.8 PAEDIATRIC HOSPICE CARE VERSUS SPECIALIST PAEDIATRIC PALLIATIVE CARE

Children's hospice care can benefit many children and their families, but it is not a substitute for good hospital or community care (Gold, 1997). It is clear from the data available that most children are cared for at home (Goldman, 1998) and that home is the right place to care for children with life-limiting conditions provided there is enough support (Dominica, 1987; Charlton, 1996; Lauer, 1997; Liben et al, 1998). However home is not always the best place or the choice of the family. Issues supporting the need for a hospice include: the family not wanting to stay in the house in which their child dies, complex symptom control and the needs of the siblings and the parents (Dominica, 1987). Contro et al (2002), reports that inadequate home care was reported by parents whose children had died at home and when they needed access to hospital services they were unavailable on an outpatient basis. Hospice care is generally regarded as respite care. The literature stresses the importance of centering paediatric palliative care around the family and the home (Hain, 2004).

Are hospices for children appropriate? The role of children's hospices needs to be clarified (Sheldon et al, 2002). Chambers (1987), questions whether it is a "well intentioned but misguided idea that will result in charitable donations being made to a project of questionable benefit to children". Lauer (1997), states that it is not the hospice building families need, but rather the philosophy of hospice care. Contro et al (2002), states that a positive relationship with the care-givers is of great importance.

There is still little evaluation of Hospices, despite continuous expansion of adult units. The same is true for paediatric hospices. Stein et al (1989) evaluated Helen House in Oxford in terms of the family's perception of the care offered. Length of admission varied from 8 days to 7 weeks. The families studied expressed the needs for care in a non-hospital environment, emotional support in a relaxed and homely environment, symptom relief rather than active treatment, and the need for respite care. Of the families studied, 72% felt well supported by Helen House. The remaining 22% felt moderately supported; they were concerned about their children being in the presence of other terminally ill children.

During the period November 1982 to December 1983, Helen House admitted 52 children, classified into 3 groups: those requiring terminal care, those with progressive and invariably fatal conditions, and those needing significant nursing care due to permanent severe handicap. This equated to a bed occupancy of 44%. Of the children admitted there were 8 deaths. (Burne, Dominica and Baum, 1984). The average number of admissions per year per child was about 4 (Dominica, 1987). In a community needs assessment performed by Toce et al (2003), parents stated that the word Hospice was "distasteful" as it removed all hope.

According to Hain (2002), the Children's Hospice Movement was met with resistance from paediatricians as it implied criticism and divided paediatricians from the movement. He notes the importance of the consultant-led multidisciplinary team that moves between hospital and community, thus allowing specialist knowledge to be taken into the child's home rather than bringing the child into the hospital. He goes on to clarify that links between hospital-led paediatric palliative care services and children's hospices are important and are developing. This concept of collaboration has been discussed in section 1.2.5 above. Hain (2004) differentiates between hospice care run by GPs offering mainly respite care and specialist paediatric palliative medicine offered by trained paediatricians. He welcomes the recent interest by paediatricians in the children's hospice movement but also feels this may detract from holistic care and cause unnecessary medicalization. It is clear in the literature that there is some conflict in the relationship between children's hospices and specialist paediatric oncology services (Farrell et al, 1998). Contro et al (2002) found that children lacked access to experts trained in paediatric hospice care.

There is a concern that free-standing hospices will provide excellent care but may disrupt the relationship between the child/family and previous care givers. (Morgan et al, 2000). Feudtner et al (2002), feel that palliative care services need to be partially hospital-based, integrated with community-based services in order to achieve continuity. This view is supported by Goldman (1990). In general it appears that there are few programmes that encompass all aspects of paediatric palliative care that are needed to deliver an effective service, namely the hospital, the home and the hospice (Contro et al, 2002).

The care given at children's hospices need not be exclusive to hospices and can be the model of care in paediatric wards as well as the community, and should be in all aspects of paediatric care (Gold, 1997). Hospice care is a philosophy of care (Dominica, 1987; Gates, 1992).

Despite a deep belief in children's hospices, Dominica (1987) concurs with many that a proliferation of children's hospices would be wasteful and feels the primary support should be in the homes of the children.

There is little information on disadvantaged children with life-limiting conditions, i.e. orphaned children living with extended family or homes, as well as children from different racial and ethnic groups (Hutton, 2002).

1.2.9 HIV/AIDS

One of the difficulties with treating HIV/AIDS is the many levels to the disease, not only physical but also on a social level. HIV/AIDS is a multi-generational, multi-system, and in infants and children, often unpredictable illness (Boland, 2000; Chaffee, 2001). The course of the disease varies from rapid progression to a later onset of symptoms and a slower progression (Chaffee, 2001). It is therefore often difficult for doctors to know when the child is dying (McKeogh and Evans, 1997; Oleske et al, 1999).

Healthcare professionals need a plan both to manage the disease actively but also to support and palliate the patient and family. Issues such as a breakdown in the family structure due to other family members having the disease, social stigmatization, poverty, lack of adequate housing and difficulties dealing with welfare organizations are some of the issues facing families dealing with HIV/AIDS. (Gary, 1992; Oleske et al, 1999).

It is important for children admitted to hospices to have the support and ongoing care of the acute-care unit (Mckeogh et al, 1996), usually a hospital or clinic facility. A high level of coordination is required to manage the complex health care and psychosocial needs of children with HIV infection (Boland, 2000).

The delivery of palliative care to children whose parents are ill or have died is more difficult as the child has lost their best advocate. These children may be cared for by extended family or by the state or privately funded homes (Oleske et al, 1999). Approximately 50-65% of children with HIV live with a family member other than a biological parent (Boland, 2000).

Data from the Francois-Xavier Bagnoud Centre for Children in New Jersey, USA shows that of the children dying from AIDS, 85% were complicated by opportunistic infections and multiple organ failure. The children had a protracted dying phase, lasting as long as 6-18 months in some cases (Oleske et al, 1999). The literature states the importance of managing these children aggressively and the crossover that exists between active and palliative treatment. Sometimes the active treatment is the best palliative treatment. Nutrition is seen as part of supportive treatment but also a critical part of health care in these patients. (Oleske et al, 1999).

Internationally, there is a lack of experience in caring for children with end-stage HIV/AIDS (Oleske et al, 1999). There is little research coming out of areas where the prevalence of HIV/AIDS is high.

Of importance is the changing face of HIV/AIDS in children, as more children are treated with combination anti-retroviral (ARV) treatments. Starting combination therapy within the first 3 months of life can cause a halt in viral replication and preserve normal immune function for years. In the USA in 2000, less than 200 babies were infected with HIV. (Sullivan and Luzuriaga, 2001). The future of caring for children with HIV will require lifelong treatment involving multidrug regimens and complex medical interventions (Boland, 2000).

1.2.10 CONCLUSION

In conclusion it can be seen that paediatric palliative care is a developing field of paediatric medicine. There are many barriers to its development that will need to be overcome and planning services will require a coordinated, flexible and collaborative approach by all groups caring for children with life-limiting illnesses.

1.3 AIMS AND OBJECTIVES

The aim of this study is to analyze the profile and management of patients admitted to the pilot paediatric unit at the Witwatersrand Hospice.

The objectives are to:

1. Analyze the data of patients admitted in terms of:
    - A demographic profile
    - Reason for admission which includes diagnosis and length of stay
    - General management and treatment
    - Outcome of admission which will include the result of the admission as well as the follow-up
2. Identify the factors influencing admission.
3. Document the management of patients in the unit.
4. Document the outcome of admission and follow-up of patients who are discharged from the unit.
5. Make recommendations for the future development of the paediatric Palliative Care Unit at Witwatersrand Hospice.

CHAPTER TWO

2 RESEARCH METHODOLOGY AND DESIGN

2.1 INTRODUCTION

In this chapter, the researcher will present the methodology and the procedures followed in this study. The methodology followed in this chapter will focus on population, research design, data collection methods and data analysis procedures.

2.2 RESEARCH DESIGN

The research design refers to all of the decisions made about how a research study is to be conducted (De Vos, 1998).

This study is a retrospective, descriptive, analytical study of data collected during admissions of paediatric patients. There are two research methods described by De Vos, (1998): quantitative and qualitative research. This research is quantitative as it produces precise and generally applicable statistical findings. This research focuses on specific, constant questions and will produce numerical and factual data thus providing for numerical and statistical analysis. The unit of measurement in this research focuses on the number of admissions rather than the number of patients and the analysis describes the overall number of admissions.

2.3 POPULATION

Population is defined as the collection of all individuals, families, groups, organizations, communities and events that one is interested in finding out more about (Mark, 1996). This population will be all the paediatric patients admitted to the Witwatersrand Paediatric Hospice Unit from the beginning of July 2003 to the end of June 2005.

2.4 ETHICAL CONSIDERATIONS

The population studied is considered vulnerable for the following reasons: they are children, they have serious, incurable illnesses, they are unable to give informed consent, many of them are orphaned, and their parents / guardians may be emotionally stressed. It is therefore important that good research and ethical standards are followed and to anticipate and minimize possible harm within the proposal (Cooley, 2000). This research does not place the child at any risk. This research is relevant. There are no monetary incentives. The consent is voluntary and refusal will not prejudice ongoing care.

On admission, the parents/guardians were given an information sheet explaining the research (Appendix 4). Two consent forms were filled in by the parent / guardian of the child. The first was consent for admission into Hospice Witwatersrand (Appendix 2). The second was a specific informed consent form for the child's clinical records to be used for this research project (Appendix 3). The patient's name did not appear on the data collection form and no photographic material was used in the study.

Ethical approval for the research study was granted by the Ethics Committee of the University of Cape Town in June 2005.

2.5 DATA COLLECTION METHOD

The data was collected by analyzing the files and notes taken of each child during the admission. The information was filled onto a data collection form (Appendix 1). The data collection form was devised by the researcher to capture specific questions with regard to the admission of each patient. Each form was completed by the researcher. All the information was taken from the time of admission until the time of discharge only. Information subsequent to discharge was not included.

2.6 DATA ANALYSIS

De Vos, 1998 describes analysis as a reasoning strategy with the objective of taking a complex whole and resolving it into its parts.

By means of numerical analysis the data was categorized under relevant headings. Using statistical analysis, the data relevant to the understanding of paediatric admissions into the palliative care unit was isolated, interpreted and reported. The patients were divided into an HIV+ and HIV- group and the 2 groups compared using different variables. The Pearson *Chi*-squareT-test, Mann-Whitney test and the Fisher Exact Test were used for statistical analysis. The purpose of cross tabulating the data is to examine frequencies of observations that belong to specific categories on more than one variable. Cross tabulations were performed between the HIV+ and HIV- group. Cross tabulations allow relationships to be identified between the variables. (Statsoft, Inc 2004). Once this was done the data was then presented in an organized manner that allowed deductions, conclusions and recommendations to be made in terms of future development of the Paediatric Palliative Care Unit.

2.7 CONCLUSION

The focus of this chapter was the research procedures followed in this study, these included: decisions about population, research design, data collection methods and data analysis procedures.

The implementation of the above methods led the researcher to obtain data which will be presented and analyzed in the next chapter.

CHAPTER THREE

3 RESEARCH RESULTS

3.1 INTRODUCTION

This chapter will look at the first objective and show the research findings on the data collected on all the paediatric admissions and decide whether these findings can assist with making recommendations for the future development of the Paediatric Palliative Care Unit at Witwatersrand Hospice.

A total of 64 data collection forms were completed and analyzed by means of numerical analysis under the following seven headings:

1. Demography
2. Diagnosis
3. Reason for admission
4. Length of admission
5. General management and treatment
6. Outcome
7. Follow-up

Cross tabulations were performed to determine statistically significant differences between patients with or without HIV/AIDS.

3.2 NUMERICAL ANALYSIS OF DATA COLLECTION FORMS

3.2.1 DEMOGRAPHY

A total of 64 patients were admitted to the Paediatric Palliative Care Unit between July 2003 and June 2004. The following data was recorded: age, sex and where or with whom the child was living.

Table 3-1 Mean age in months of children in study

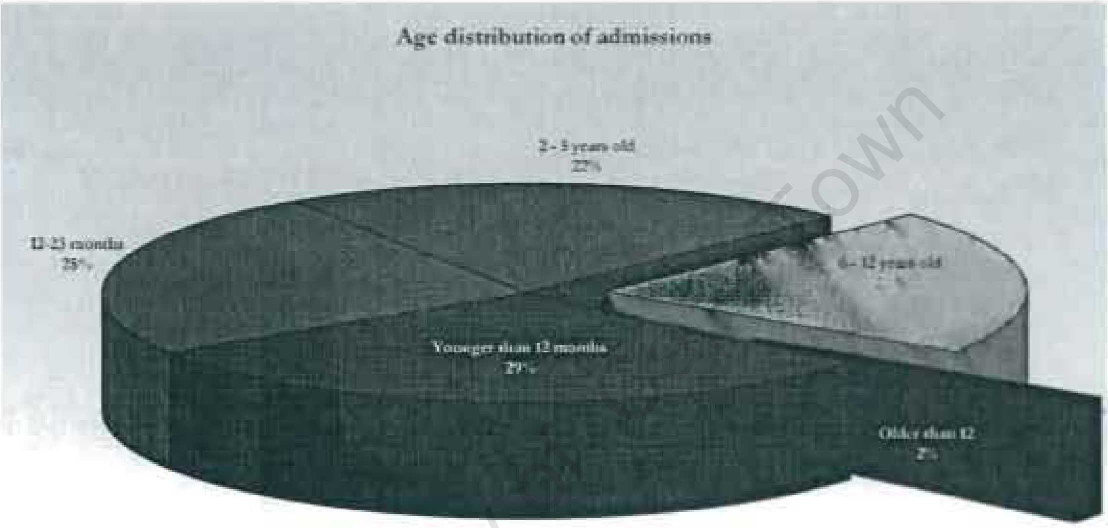
	Mean	Median	Std. Deviation	Skewness	Kurtosis
Age (months)	40.38	20.00	42.047	1.361	1.106

From Table 3-1 there is a noticeable difference between the mean and the median value and the reason for this is that there were 14 children older than 5 years which gives the mean value a much higher than would be expected value. The median corrects for this wide distribution.

Table 3-2 Categories of ages of children in study

		Frequency	Percent
Valid	Younger than 12 months	19	29.7
	12-23 months	16	25.0
	2 - 5 years old	14	21.9
	6 - 12 years old	14	21.9
	Older than 12	1	1.6
	Total	64	100.0

Figure 3 Pie Diagram of categories of ages



The youngest patient was 3 months old and the oldest was 15 years old. As can be seen in Figure 3, 76.6% of admissions were younger than 5 years of age. The majority (54.7%) were less than 24 months of age.

Table 3-3 Gender of children in study

		Frequency	Percent
Valid	Male	27	42.2
	Female	37	57.8
	Total	64	100.0

From table 3-3 the male to female ratio was 3: 4.

Table 3-4 Place of living of children in study

		Frequency	Percent
Valid	Family	28	43.8
	Institution	36	56.2
	Total	64	100.0
Total		64	100.0

Note: Family refers to one or both parents or extended family

Table 3-5 The total no. of children with HIV/AIDS living with family compared to Children's Homes

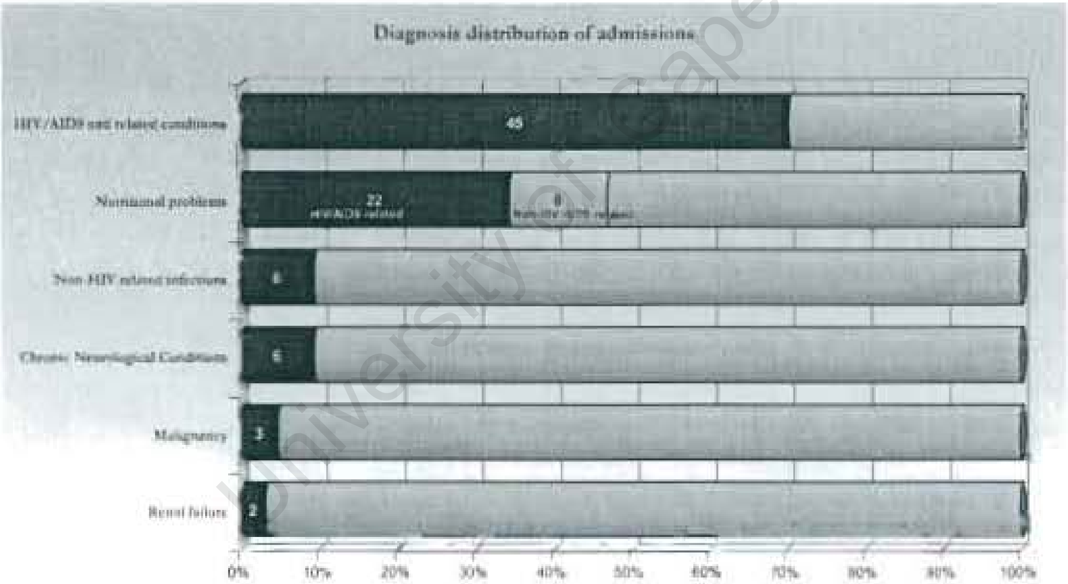
		Living with		Total
		Family	Institution	
Diagnosis: HIV/AIDS	Count	18	27	45
	%	40.0%	60.0%	100.0%

From Table 3-4 the ratio of children living with relatives at home compared to Children's Homes was 3:4 which was higher than expected. As seen in Table 3-5 the ratio of HIV+ve children living with relatives at home to Children's Homes was 2: 3 which was also higher. Many of the children in the Children's Homes were abandoned or orphaned but this was not examined in this study. A few of the children had mothers who roomed in with them but this was also not studied in this research.

3.2.2 DIAGNOSIS

Taking into account the repeat admissions (see Section 3.2.4 below), the most common diagnoses were:

Figure 4 **Diagnosis distribution of admissions**



Bradshaw et al, (2003) refers to protein-energy malnutrition in the Burden of Disease study. For this study, this has been referred to as Nutritional Problems (ICD10 code E64) because it incorporates more than marasmus and kwashiorkor. The children were often admitted because of failure to thrive, oral candidiasis or chronic gastro-enteritis, or had feeding problems related to reflux, prematurity, and swallowing difficulties.

Non-HIV related infections incorporated the following: neonatal CMV (ICD10 P35.1), lower respiratory infections (ICD10 J21.8, J18.0) and *streptococcal pneumonia* meningitis (ICD10 G00.9).

Chronic neurological conditions comprised hypotonic cerebral palsy (ICD10 G80.9), spastic cerebral palsy (ICD10 G80.9), microcephaly (ICD10 Q02) and spinal muscular atrophy (ICD10 G12.9)).

The patients admitted with malignancy suffered from acute lymphoblastic leukaemia (ICD10 C91.0), neuroblastoma (ICD10 M9500/3) and squamous cell cancer of the tongue (ICD10 C02.9).

Table 3-6 Diagnosis distribution of admissions

	Frequency	Percent
HIV/AIDS and related conditions	45	70.31
Nutritional problems - HIV/AIDS related	22	34.38
Nutritional problems - Non-HIV/AIDS related	8	12.50
Non-HIV/AIDS related infections	6	9.38
Chronic Neurological Conditions	6	9.38
Malignancy	3	4.69
Renal failure	2	3.13

Table 3-7 Categories of diagnoses

Diagnosis		
HIV/AIDS	Count	45
	%	70.3%
TB	Count	24
	%	37.5%
Other infections	Count	43
	%	67.2%
Pulmonary	Count	25
	%	39.1%
Malignancy	Count	3
	%	4.7%
Nutritional	Count	30
	%	46.9%
Wounds	Count	2
	%	3.1%
Renal	Count	3
	%	4.7%
Neurological	Count	24
	%	37.5%

The purpose of this table is to show that many children admitted had more than one diagnosis with overlap particularly with HIV, TB, other infections, nutritional deficiency and neurological disorders. Table 3-7 divides the diagnoses into a number of categories. TB refers predominantly to Pulmonary TB but it also includes extra-pulmonary TB. Other infections refers to all infections other than TB. Pulmonary refers to problems of lung infections, pulmonary TB, chronic lung disease, and cor pulmonale (strictly speaking cor pulmonale should be classified under cardiac but it has been included here for sake of simplicity). Neurological refers to primary chronic neurological problems such as cerebral palsy and spinal muscular atrophy as well as secondary problems such as

TB meningitis and other cerebral infections, HIV encephalopathy, cerebral vasculitis and spinal cord compression from metastasis.

Table 3-8 Age according to diagnosis

Diagnosis	Mean Age	
	Months	Years
HIV/AIDS	44.1	3.7
Malignancy	117.7	9.8
Neurological	28.0	2.3
Renal failure	44.0	3.7
Nutritional problems	36.4	3.0

From Table 3-8 the mean age of known HIV infected children was 3.7 years and that of children with malignancy, 9.8 years. The age of patients with malignancy was 2-3 times greater than all the other conditions.

Table 3-9 Categories of HIV/AIDS diagnoses

		Frequency	Percent
Valid	HIV/AIDS negative	19	29.7
	Category A HIV/AIDS	1	1.6
	Category B HIV/AIDS	2	3.1
	Category C HIV/AIDS	42	65.6
	Total	64	100.0

As noted from Table 3-9 the majority of admissions for HIV/AIDS were patients in Category C. (See Appendix 7). The data collection form was drawn up using the Centre for Disease Control (CDC) criteria for diagnosing HIV infection. Subsequent to this

WHO released an updated clinical staging of HIV/AIDS for infants and children. This has been included as Appendix 8.

3.2.3 REASON FOR ADMISSION

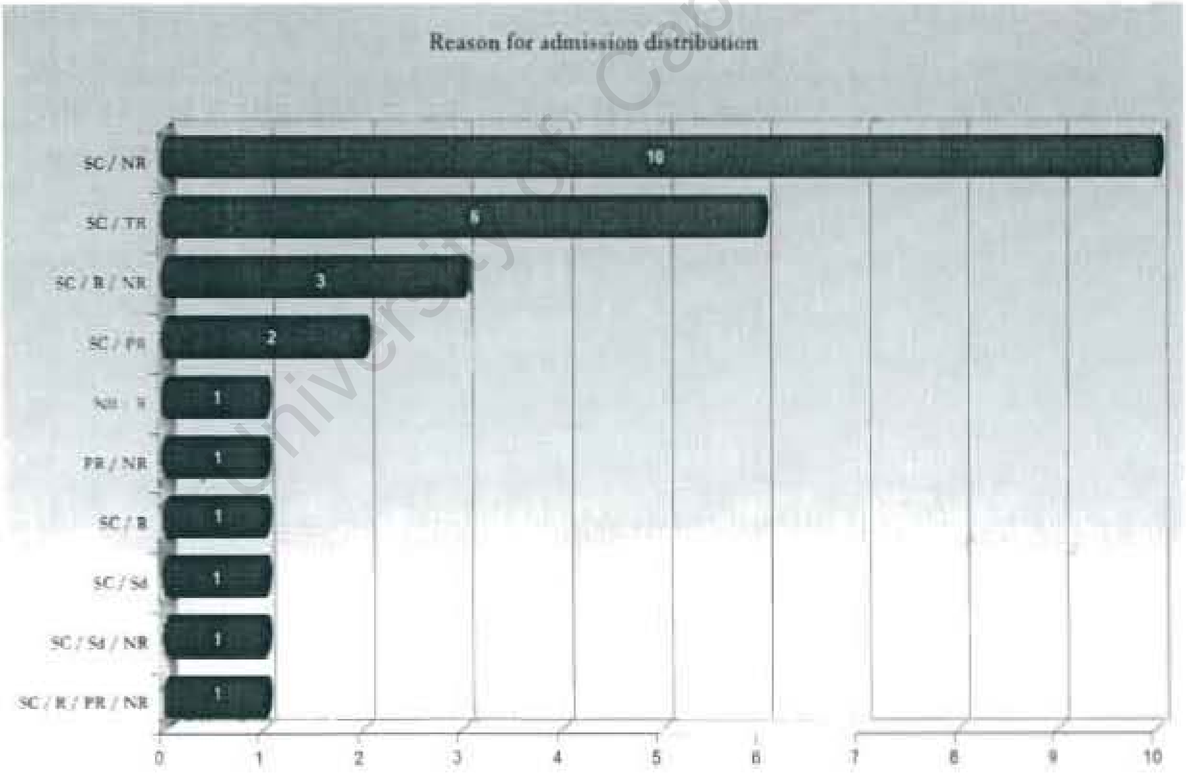
The criteria for admission into the unit were devised in collaboration with the CHOMP paediatrician, paediatric hospital consultants and Hospice doctors (Appendix 6). The reasons for admission for this study were summarized into the following categories on the data collection forms: symptom control, respite care, terminal care, step-down care, nutritional rehabilitation and procedure related care. Nutritional rehabilitation is included here as a reason for admission as it was more for a trial of feeding/change of nutrition/nasogastric feeds that the child was admitted. Nutritional problems was included as a diagnosis because it tended to incorporate the pathology behind the problem.

Table 3-10 Reasons for admission of children

Reason for admission		Yes
Symptom control	Count	42
	%	65.6%
Respite	Count	11
	%	17.2%
Step Down	Count	5
	%	7.8%
Nutritional rehabilitation	Count	21
	%	32.8%
Terminal Care	Count	14
	%	21.9%
Procedure	Count	6
	%	9.4%

From table 3-10 symptom control was the main reason for Hospice admission (65.6%) with nutritional rehabilitation (32.8%) and respite (17.2) also being important reasons for admission. Of those patients admitted, nearly 50% were admitted for more than one reason (Figure 5). The majority (37.0%) of these patients were admitted for symptom control and nutritional rehabilitation (Figure 5).

Figure 5 **Number of patients with multiple reasons for admission**



KEY
SC – Symptom control
NR – Nutritional rehabilitation
TC – Terminal care
PR – Procedure related
SD – Step down

3.2.4 LENGTH OF ADMISSION

Table 3-11 Categories of length of admission

		Frequency	Percent
Valid	1-2 days	5	7.8
	3 - 7 days	10	15.6
	8 - 14 days	18	28.1
	15 - 28 days	16	25.0
	More than 4 weeks	15	23.4
	Total	64	100.0

Table 3-12 Mean duration of admission in days

	Mean	Median	Std. Deviation	Skewness	Kurtosis
Duration of admission (days)	18.81	14.00	17.072	1.727	2.899

From table 3-12 the median admission time was 14.00 days with the shortest admission being 1 day and the longest being 80 days. As seen in Table 3-11, 50% of all admissions were admitted for more than 14 days and half of these were over 30 days. A total of 15 (23.4%) patients were admitted for more than 1 month and 3 for more than 2 months.

Figure 6 **Graph showing mean daily bed occupancy**

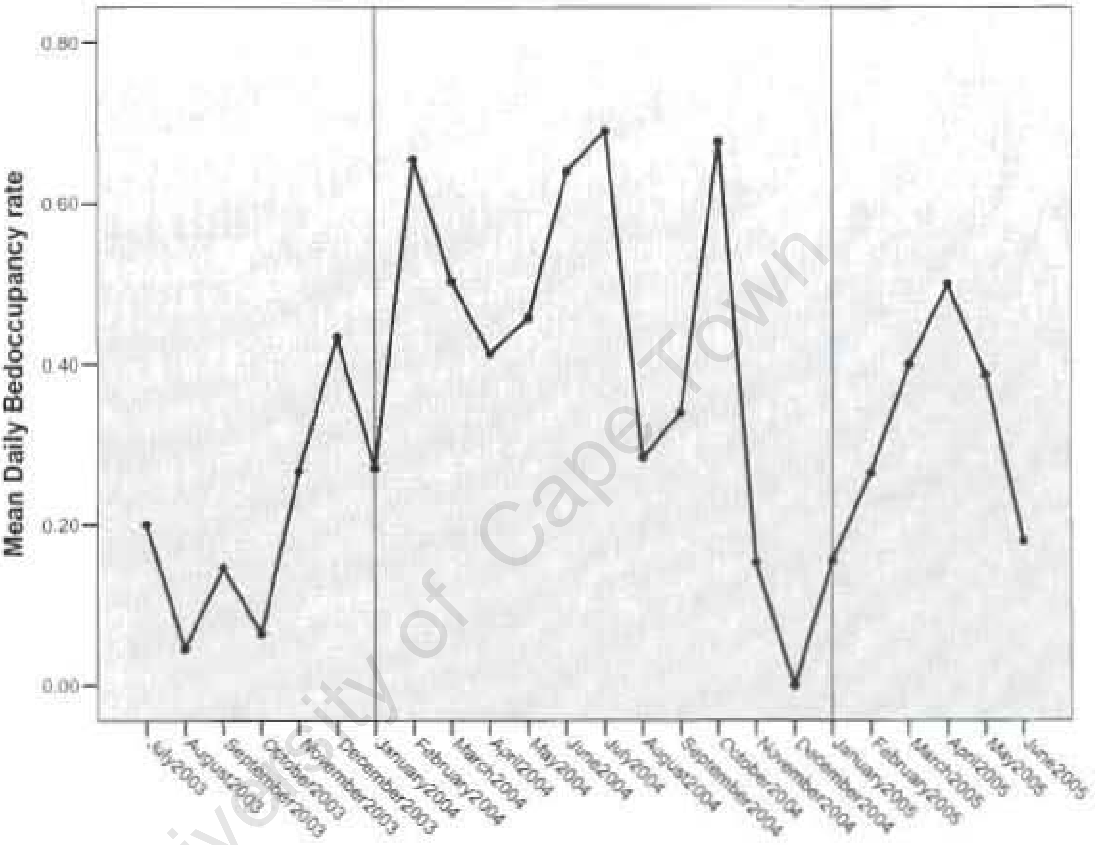


Table 3-13 **Mean daily bed occupancy**

N	702
Mean	.3439
Std. Deviation	.26121

Table 3-14 Number of admissions over 2 year period

6-Month Period	No. of admissions
July-December 2003	11
January-June 2004	28
July-December 2004	7
January-June 2005	13

There was a total of 64 admissions over the 2 year period studied. Figure 3 shows the graph depicting mean daily bed occupancy rate. Table 3-14 shows the numbers of patients admitted in each 6-month period. There were at any given time 5 beds available for paediatric patients which translated to a total availability of 3510 bed days. Table 3-13 shows the mean daily bed occupancy at 34.4%

A total number of 6 children were admitted more than once. Two children had 3 admissions each and 4 children were admitted twice.

3.2.5 GENERAL MANAGEMENT AND TREATMENT

For ease of data collection, the treatment was divided into disease specific treatment geared towards cure, palliative treatment aimed at securing good quality of life, treatments involving both disease specific and palliative components and nutritional rehabilitation. Disease specific treatment included anti-retroviral therapy (ART), TB medication, antibiotics and chemotherapy. Palliative treatment included pain and symptom control.

Table 3-15 Categories of treatment

Treatment		
Disease specific (DS)	Count	6
	%	9.4%
Palliative (P)	Count	8
	%	12.5%
Both DS & P	Count	49
	%	76.6%
Nutritional	Count	27
	%	42.2%

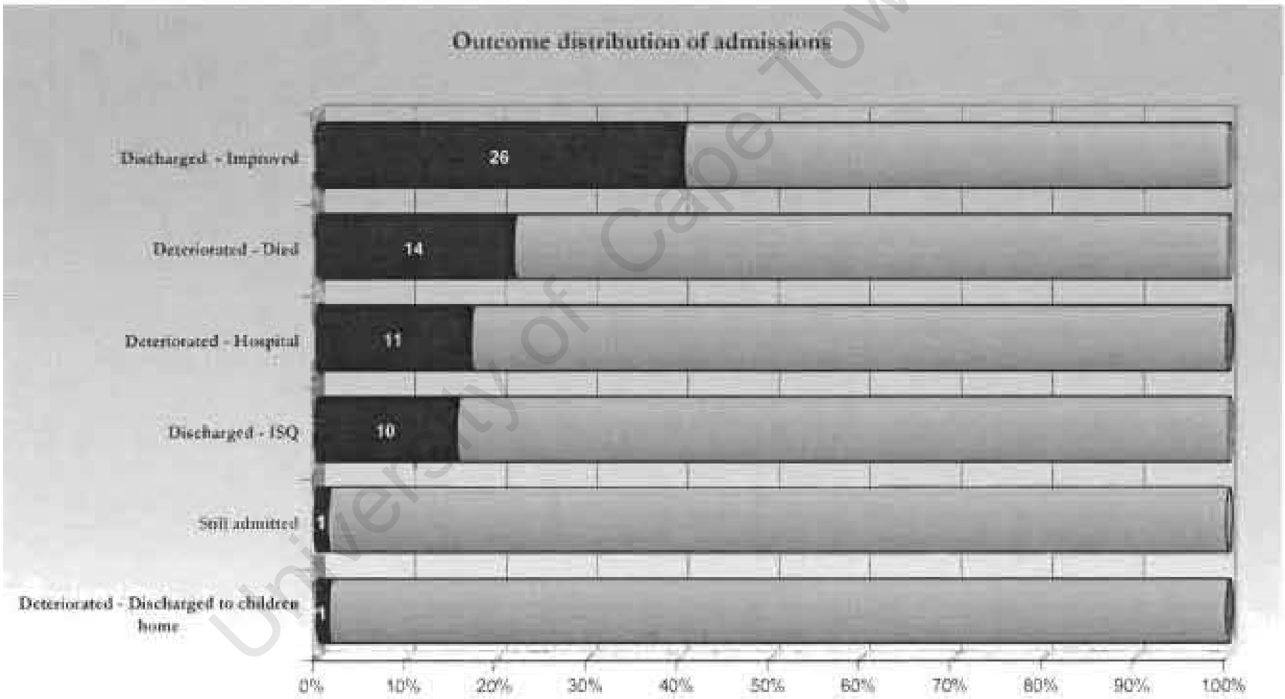
From Table 3-15, 76.6% of children required both palliative and disease specific treatment and a high proportion (42.2%) required nutritional therapy. Children requiring disease specific treatment or palliative treatment alone were low in proportion, 9.4% and

12.5% respectively. Of the total number of HIV+ admissions, 28.89% were treated with ART. Most of the children were already on ART at admission but a few were admitted specifically to start ART under supervision. During the first year, 17.39% of HIV+ children were treated with ART and this increased to 40.90% during the second year.

3.2.6 THE OUTCOME

The following categories were included on the data collection form: improvement and discharge home; condition remaining the same and discharged home; deterioration and transferal to hospital; and deterioration and death. At the close of data collection, one child included was still in the unit.

Figure 7 Categories of outcome of admissions



From Figure 7, 57.8% of patients were discharged from Hospice of which 40.6% were improved in their condition, 15.6% were the same as on admission and 1 child had deteriorated. A total of 21.9% of patients died in the unit. The remaining 17.2% of patients were transferred to hospital because of deterioration in condition. The majority of these transfers (63.6%) were due to HIV/AIDS related illnesses. (Table 3-16)

Table 3-16 **Children transferred to hospital**

Diagnosis		
HIV/AIDS	**Count**	7
	%	**63.6%**
Chronic Neurological Disorders	**Count**	3
	%	**27.3%**
Renal Failure	**Count**	1
	%	**9.1%**

Table 3-17 **Children who died in the Unit**

Diagnosis		
Category C HIV/AIDS	**Count**	10
	%	71.4%
Malignancy	**Count**	2
	%	14.3%
Category B HIV/AIDS	**Count**	1
	%	7.1%
Renal Failure	**Count**	1
	%	7.1%

3.2.7 THE FOLLOW-UP

The following categories of follow-up were included on the data collection forms: CHOMP, Hospital and Hospice Home Care.

Table 3-18 Categories of follow-up of children

Follow-up: Hospice home care	**Count**	7
	%	10.9%
Follow-up: CHOMP	**Count**	31
	%	48.4%
Follow-up: Hospital clinic	**Count**	46
	%	71.9%

From Table 3-18 it is clear that the majority of patients were followed up by hospital (71.9%) and CHOMP (48.4%). Hospice had little (10.9%) home care follow-up of patients.

Table 3-19 Categories of combination follow-up

	Frequency	Percent
CHOMP / Hospice	0	0
CHOMP / Hospice / Hospital	1	1.56
Hospice/ Hospital	6	9.38
CHOMP / Hospital	29	45.31
Total	64	100.0

As seen in Table 3-19 a number of children were followed up by a combination of services with 45.3% of all children having follow-up from both CHOMP and the hospital.

3.3 STATISTICAL ANALYSIS OF DATA

A number of cross tabulations were done comparing children with HIV/AIDS and those without. As children with HIV/AIDS were the major admission, comparisons were made to establish possible associations with other significant pathologies between children suffering from HIV/AIDS and those not. The following tables represent cross tabulations between HIV positive and negative children.

Demographically, there was no correlation between HIV and gender. There was insufficient evidence to suggest a dependency between HIV/AIDS and where or with whom the child was living, even though the largest group of children living in institutions was suffering from HIV/AIDS (60.0%).

Table 3-20 Cross tabulation of HIV/AIDS against a diagnosis of TB

			Diagnosis: TB		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	19	0	19
		% within Diagnosis: HIV/AIDS	100.0%	.0%	100.0%
	Yes	Count	21	24	45
		% within Diagnosis: HIV/AIDS	46.7%	53.3%	100.0%
Total		Count	40	24	64
		% within Diagnosis: HIV/AIDS	62.5%	37.5%	100.0%

Table 3-21 Chi-square tests of HIV/AIDS against a diagnosis of TB

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	16.213(b)	1	.000		
Continuity Correction(a)	14.018	1	.000		
Likelihood Ratio	22.497	1	.000		
Fisher's Exact Test				.000	.000
Linear-by-Linear Association	15.960	1	.000		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 0 cells (.0%) have expected count less than 5. The minimum expected count is 7.13.					

From Table 3-20 none of the HIV-ve group had TB and more than half (53.3%) of the HIV/AIDS group had TB. From table 3-21, a significant difference is evident between the 2 groups, as the p-value was 0.000 which shows there was a statistical dependency between HIV/AIDS and TB.

Table 3-22 Cross tabulation of HIV/AIDS against a diagnosis of other infections

			Diagnosis: Other infections		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	8	11	19
		% within Diagnosis: HIV/AIDS	42.1%	57.9%	100.0%
	Yes	Count	13	32	45
		% within Diagnosis: HIV/AIDS	28.9%	71.1%	100.0%
Total		Count	21	43	64
		% within Diagnosis: HIV/AIDS	32.8%	67.2%	100.0%

There was no statistical dependency between HIV/AIDS and other infections specifically. The incidence of infections (Table 3-22) was high in both HIV+ and HIV- children. Two-thirds (67.2%) of all patients had some form of infection during their admission to hospice.

Table 3-23 Cross tabulation of HIV/AIDS against a diagnosis of pulmonary conditions

			Diagnosis: Pulmonary		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	14	5	19
		% within Diagnosis: HIV/AIDS	73.7%	26.3%	100.0%
	Yes	Count	25	20	45
		% within Diagnosis: HIV/AIDS	55.6%	44.4%	100.0%
Total		Count	39	25	64
		% within Diagnosis: HIV/AIDS	60.9%	39.1%	100.0%

From Table 3-24, 26.3% of HIV-ve children had chest pathology during their admission versus 44.4% of HIV/AIDS children. There was no statistical dependency between HIV/AIDS children and pulmonary pathology which included TB.

Table 3-24 Cross tabulation of HIV/AIDS against a diagnosis of malignancy

			Diagnosis: Malignancy		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	16	3	19
		% within Diagnosis: HIV/AIDS	84.2%	15.8%	100.0%
	Yes	Count	45	0	45
		% within Diagnosis: HIV/AIDS	100.0%	.0%	100.0%
Total		Count	61	3	64
		% within Diagnosis: HIV/AIDS	95.3%	4.7%	100.0%

Table 3-25 Chi-square tests of HIV/AIDS against a diagnosis of malignancy

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	7.455(b)	1	.006		
Continuity Correction(a)	4.339	1	.037		
Likelihood Ratio	7.645	1	.006		
Fisher's Exact Test				.023	.023
Linear-by-Linear Association	7.338	1	.007		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 2 cells (50.0%) have expected count less than 5. The minimum expected count is .89.					

From table 3-26, it is clear that if a child was admitted with a malignancy they were unlikely to have HIV/AIDS, although the population of children suffering from malignancy is very small in this study. Table 3-27 shows a statistically significant exclusive relationship between HIV/AIDS and malignancy with a p-value of 0.023.

Table 3-26 Cross tabulation of HIV/AIDS against a diagnosis of nutritional rehabilitation

			Diagnosis: Nutritional		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	11	8	19
		% within Diagnosis: HIV/AIDS	57.9%	42.1%	100.0%
	Yes	Count	23	22	45
		% within Diagnosis: HIV/AIDS	51.1%	48.9%	100.0%
Total		Count	34	30	64
		% within Diagnosis: HIV/AIDS	53.1%	46.9%	100.0%

From the above table, both HIV+ and HIV- children needed some form of nutritional rehabilitation during their admission. There was insufficient evidence to suggest a dependency between HIV/AIDS and need for nutritional rehabilitation. Both groups needed attention to nutritional requirements and that nutritional problems were equally prevalent in the population studied.

Table 3-27 Cross tabulation of HIV/AIDS against a diagnosis of neurological problems

			Diagnosis: Neurological		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	10	9	19
		% within Diagnosis: HIV/AIDS	52.6%	47.4%	100.0%
	Yes	Count	30	15	45
		% within Diagnosis: HIV/AIDS	66.7%	33.3%	100.0%
Total		Count	40	24	64
		% within Diagnosis: HIV/AIDS	62.5%	37.5%	100.0%

From Table 3-30, there was an equal prevalence of neurological problems between the HIV+ and HIV- group. Just over a third (37.5%) of children had some form of primary or secondary neurological impairment or problem at the time of their admission. There was no statistical dependency demonstrated between HIV/AIDS and neurological problems.

Table 3-28 Cross tabulation of HIV/AIDS against symptom control as reason for admission

			Reason for admission: Symptom control		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	11	8	19
		% within Diagnosis: HIV/AIDS	57.9%	42.1%	100.0%
	Yes	Count	11	34	45
		% within Diagnosis: HIV/AIDS	24.4%	75.6%	100.0%
Total		Count	22	42	64
		% within Diagnosis: HIV/AIDS	34.4%	65.6%	100.0%

Table 3-29 Chi-square tests of HIV/AIDS against symptom control as reason for admission

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.626(b)	1	.010		
Continuity Correction(a)	5.226	1	.022		
Likelihood Ratio	6.450	1	.011		
Fisher's Exact Test				.020	.012
Linear-by-Linear Association	6.523	1	.011		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 0 cells (.0%) have expected count less than 5. The minimum expected count is 6.53.					

As shown in Table 3-32, an HIV/AIDS +ve admission was more likely (65.6%) to be admitted for symptom control than if the child was suffering from a non-HIV/AIDS condition. Table 3-33 shows a statistically significant dependency between HIV/AIDS and admission for symptom control with the p-value of 0.020.

Table 3-30 Cross tabulation of HIV/AIDS against respite as reason for admission

			Reason for admission: Respite		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	12	7	19
		% within Diagnosis: HIV/AIDS	63.2%	36.8%	100.0%
	Yes	Count	41	4	45
		% within Diagnosis: HIV/AIDS	91.1%	8.9%	100.0%
Total		Count	53	11	64
		% within Diagnosis: HIV/AIDS	82.8%	17.2%	100.0%

Table 3-31 Chi-square tests of HIV/AIDS against respite as reason for admission

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	7.334(b)	1	.007		
Continuity Correction(a)	5.502	1	.019		
Likelihood Ratio	6.728	1	.009		
Fisher's Exact Test				.012	.012
Linear-by-Linear Association	7.219	1	.007		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 1 cells (25.0%) have expected count less than 5. The minimum expected count is 3.27.					

Table 3-34 shows that if the child was admitted for HIV/AIDS it was unlikely to be for reasons of respite (8.9%) compared to children without HIV/AIDS where it was likely to be 36.8%. From table 3-35, a statistically significant independency is shown between HIV/AIDS and the need for admission for respite with the p-value of 0.012.

Table 3-32 Cross tabulation of HIV/AIDS against nutritional rehabilitation as reason for admission

			Reason for admission: Nutritional rehab		Total
			No	Yes	
Diagnosis: HIV/AIDS	**No**	**Count**	12	7	19
		% within Diagnosis: HIV/AIDS	63.2%	36.8%	100.0%
	Yes	**Count**	31	14	45
		% within Diagnosis: HIV/AIDS	68.9%	31.1%	100.0%
Total		**Count**	43	21	64
		% within Diagnosis: HIV/AIDS	67.2%	32.8%	100.0%

Table 3-36 shows that there was an equal need for nutritional rehabilitation in both the HIV+ and HIV- group and therefore no statistical difference noted.

Table 3-33 Cross tabulation of HIV/AIDS against terminal care as reason for admission

			Reason for admission: Terminal Care		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	12	7	19
		% within Diagnosis: HIV/AIDS	63.2%	36.8%	100.0%
	Yes	Count	38	7	45
		% within Diagnosis: HIV/AIDS	84.4%	15.6%	100.0%
Total		Count	50	14	64
		% within Diagnosis: HIV/AIDS	78.1%	21.9%	100.0%

There was no statistically significant dependency demonstrated between HIV/AIDS admissions and terminal care. However there is a trend towards an association and had the population been bigger it may have been significant. The data (Table 3-38) indicates that if the child is admitted for HIV/AIDS it is less likely (21.9%) to be for terminal care compared to the HIV/AIDS –ve group who were more likely (78.1%) to be admitted for terminal care.

Table 3-34 Cross tabulation of HIV/AIDS against disease specific treatment

			Treatment: Disease specific (DS)		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	16	3	19
		% within Diagnosis: HIV/AIDS	84.2%	15.8%	100.0%
	Yes	Count	42	3	45
		% within Diagnosis: HIV/AIDS	93.3%	6.7%	100.0%
Total		Count	58	6	64
		% within Diagnosis: HIV/AIDS	90.6%	9.4%	100.0%

As seen in Table 40, there was a low incidence of patients treated with only disease specific treatment in both the HIV- and HIV+ group.

Table 3-35 Cross tabulation of HIV/AIDS against palliative treatment

			Treatment: Palliative		**Total**
			No	**Yes**	
Diagnosis: HIV/AIDS	**No**	**Count**	13	6	19
		% within Diagnosis: HIV/AIDS	68.4%	31.6%	100.0%
	Yes	**Count**	43	2	45
		% within Diagnosis: HIV/AIDS	95.6%	4.4%	100.0%
Total		**Count**	56	8	64
		% within Diagnosis: HIV/AIDS	87.5%	12.5%	100.0%

Table 3-36 Chi-square tests of HIV/AIDS against palliative treatment

	Value	**df**	**Asymp. Sig. (2-sided)**	**Exact Sig. (2-sided)**	**Exact Sig. (1-sided)**
Pearson Chi-Square	8.993(b)	1	.003		
Continuity Correction(a)	6.683	1	.010		
Likelihood Ratio	8.164	1	.004		
Fisher's Exact Test				.007	.007
Linear-by-Linear Association	8.853	1	.003		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 1 cells (25.0%) have expected count less than 5. The minimum expected count is 2.38.					

Table 3-42 shows that if a child had HIV/AIDS it was less likely (4.4%) to have palliative care alone than a child admitted for conditions other than HIV/AIDS (87.5%). From Table 3-43, a significant difference is evident between the 2 groups, as the p-value was 0.007 which shows there was a statistically significant exclusive relationship between HIV/AIDS and treatment with palliative care alone.

Table 3-37 Cross tabulation of HIV/AIDS against both disease specific and palliative treatment

			Treatment: Both DS & P		Total
			No	Yes	
Diagnosis: HIV/AIDS	No	Count	10	9	19
		% within Diagnosis: HIV/AIDS	52.6%	47.4%	100.0%
	Yes	Count	5	40	45
		% within Diagnosis: HIV/AIDS	11.1%	88.9%	100.0%
Total		Count	15	49	64
		% within Diagnosis: HIV/AIDS	23.4%	76.6%	100.0%

Table 3-38 Chi-square tests of HIV/AIDS against both disease specific and palliative treatment

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	12.835(b)	1	.000		
Continuity Correction(a)	10.625	1	.001		
Likelihood Ratio	12.015	1	.001		
Fisher's Exact Test				.001	.001
Linear-by-Linear Association	12.634	1	.000		
N of Valid Cases	64				
a Computed only for a 2x2 table					
b 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.45.					

Table 3-44 shows that a child with HIV/AIDS was more likely (76.6%) to require both palliative and disease specific treatment than children without HIV/AIDS. As seen in Table 3-45 a significant difference is evident between the patients with and without HIV/AIDS, as shown by the p-value of 0.001 indicating a statistically significant dependency between HIV/AIDS and treatment that was both disease specific and palliative.

Table 3-39 Cross tabulation of HIV/AIDS against nutritional treatment

			Treatment: Nutritional		Total
			No	Yes	
Diagnosis: HIV/AIDS	**No**	**Count**	12	7	19
		% within Diagnosis: HIV/AIDS	63.2%	36.8%	100.0%
	Yes	**Count**	25	20	45
		% within Diagnosis: HIV/AIDS	55.6%	44.4%	100.0%
Total		**Count**	37	27	64
		% within Diagnosis: HIV/AIDS	57.8%	42.2%	100.0%

As seen in table 3-46, both HIV+ve and HIV-ve patients (42.2%) required nutritional treatment. As a result there was no statistical correlation between HIV+ve and HIV-ve patients.

3.4 CONCLUSION

The focus of this chapter was to show the research findings on the data collected on 64 paediatric patients and present them using numerical and statistical analysis.

The above results led the researcher to a discussion and to formulate recommendations.

CHAPTER FOUR

4 DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

The focus of this study was to analyze the profile and management of patients admitted to the paediatric unit at the Witwatersrand Hospice, Johannesburg in order to make recommendations for expanding the unit.

Data was analyzed by completing 64 data-capturing forms designed in accordance with Objective 1 in this study, as laid out in Chapter 1. The data captured from the data collection form has been presented in Chapter 3. A discussion of the results will now be provided with Objectives 2, 3 and 4 in mind.

The above-mentioned objectives are:

1. To analyze the data of patients admitted in terms of a demographic profile, the reason for admission including diagnosis and length of stay, the general management and treatment and the outcome of each admission including the result of the admission as well as the follow-up.
2. To identify factors influencing admission.
3. To document the management of patients in the unit.
4. To document the outcome of admission and follow-up of patients who are discharged from the unit.

4.2 DISCUSSION OF DATA OBTAINED

4.2.1 DEMOGRAPHY

The group studied was of an average age of 3.37 years and a ratio of male to female of 3: 4. The range of ages of children admitted was large, with the youngest being 3 months and the oldest 15 years. The international literature states that diversity in terms of ages and developmental stages creates difficulties in planning paediatric palliative care (Corr, 1985). The children with malignancy were significantly older than the rest of the group which is in keeping with the literature in which cancer is the second most common cause of death in the USA, in the 5-14 year age group and only the third commonest cause of death in the 1-4 year age group (Arias et al, 2003). In South Africa, malignancy did not feature in the top 10 causes of death in the 0-5 year and 5-14 year age groups but the figures conceal variations between population groups in terms of socioeconomic status.

In terms of numbers of admissions there was an upward trend for the first year of the study and then a definite fall off. The percentage (%) bed occupancy was lower than expected at 34.4% and falls well below the international figure of 44% (Burne et al, 1984). The concern is whether this % bed occupancy and the number of admissions support the further development of the paediatric unit? According to Himelstein et al (2004), very few children are admitted to paediatric hospices and only 0.4% of all hospice admissions are children. A total of 64 patients were admitted during the 2 year period compared to 52 patients admitted to Helen House in England during a 1 year period (Burne et al, 1984). This could be explained by the number of repeat admissions overseas. Of the 64 admissions here, most were admitted once except for 6 children who were admitted between 2 and 3 times during the study period. This was considerably lower than the figures quoted by Dominica (1987), where the average number of admissions per year per child is 4. There are a few reasons why this may be the case in this study. Many of the children are carefully placed in Homes that will be able to manage their conditions, the children are well followed up with CHOMP and the hospitals, more children are being treated with antiretroviral drugs, the patients with cancer tend to be admitted in the terminal phase and therefore repeat admissions are not necessary.

There was a slightly lower prevalence of children admitted to the unit living at home with relatives (which included parent(s) or extended family) than those in Children's Homes. Although 60% of children with HIV/AIDS admitted were living in institutions, there was a lack of statistical correlation between HIV/AIDS and those living in Children's Homes. The literature suggests that a higher proportion (around 50-65%) of children with HIV infection live with extended family (Boland, 2000) compared to this study where only 40% of the children where living with family.. This indicates the negative impact that HIV/AIDS has on the family structure. A closer look at who comprises the relatives and how many of the children have parents is of interest but not examined in this report. It is important to note the selection bias here; the unit was initially only open to admissions from Children's Homes and later extended to include hospitals. Admissions from hospital depended on hospital doctors, who may be reluctant to refer to Hospice (Gates, 1992; Goldman, 2000).

4.2.2 DIAGNOSIS

HIV/AIDS was the largest group of patients admitted (70.3%) which was expected as the reason for starting the unit was to provide a service to children admitted from Children's

Homes who were infected with HIV. This also ties in with the high HIV/AIDS figures in South Africa; the general prevalence of HIV/AIDS is at least 10.9% (UNAIDS, 2003). The non-HIV group comprised 30.4% and was largely admitted from the hospitals independently of CHOMP. The non-HIV group comprised malignancy, chronic neurological conditions, renal failure and non-HIV related infection. The patients with malignancy comprised a small group of older children as discussed above. Once again the diversity of patients admitted here compares with the spectrum of patients with life-limiting conditions requiring palliative medicine as established by ACT in 2003. Many of the patients studied here had multiple diagnoses which is in keeping with the complexity and diversity of illness found in children as opposed to adults as discussed by Corr (1985). According to Doyle (1998) the majority of paediatric hospice admissions are for children suffering from progressive, long-lasting and life-limiting diseases.

There was a high incidence of TB among the HIV/AIDS group of patients (53.3%) and a significant correlation between TB and HIV+ve patients. This highlights the importance of the relationship between TB and HIV/AIDS. When admitting HIV/AIDS patients, staff must have a high suspicion of TB. Many anti-TB medications have drug interactions with ARV and hospice staff will need to be aware of these. Children with cavitatory TB may pose a risk for health care workers and other patients.

The incidence of other infections in the patients both with and without HIV/AIDS was high and of equal prevalence (67.2%). Most patients requiring palliative care have chronic life-limiting illnesses predisposing them to infections.

Neurological problems were equally common in HIV+ve and HIV-ve patients (37.5%). This is most likely because many advanced diseases result in some neurological manifestation as they progress.

4.2.3 REASON FOR ADMISSION

Symptom control (65.6%) was the main reason for hospice admission, with nutritional rehabilitation (32.8%) and respite (17.2%) being the next most important reasons. The reason for admission tied in with the Admission Criteria laid down by the hospice doctors and paediatricians (Appendix 6). There were clear differences between reasons for admission between patients suffering from HIV and those with other conditions. The HIV group required more symptom control than the non HIV group who required more respite and terminal care, which points to the fact that HIV/AIDS is a more long-term, chronic life-limiting condition. It is important to note however, that many HIV related "symptoms" are a reflection of opportunistic infections due to underlying immune compromise which is the major feature of the disease and more of an important feature than other life limiting illnesses where immune function is better preserved. Also the hospitals are not admitting as much as they should for symptom control (e.g. diarrhoea) because the service is overburdened. The international literature strongly advocates that palliative care must be for children imminently dying as well as those living with chronic, potentially life-threatening conditions (Toce et al, 2003). This ties in with the argument promoting the integrated model of palliative care (figure 2) resulting in the introduction of palliative care early in the disease thereby providing both disease-specific therapy as well as supportive care (Kane et al, 2000). Internationally, respite care is considered essential (Corr, 1985; Liben and Goldman, 1998; Horsburgh et al, 2002). According to Doyle (1998), the majority of hospice admissions for children are for respite. The figures for respite care in this study are low (17.2%) which may reflect the geographical difficulties in accessing hospice care for many people. In the study of Helen House in 1984 by Burne et al, children were admitted for terminal care, respite care and nursing care.

There was a low incidence (7.8%) of patients admitted for step-down care. This most likely indicates that patients requiring step-down care were either kept for a longer time in the hospital or were transferred directly to the Children's Home or the relative's home.

The incidence of procedures performed was low (9.4%) with the majority of procedures performed by the paediatrician as opposed to the hospice doctors. Patients requiring procedures were sent to hospital. Hospice had not promoted themselves as a unit able to perform procedures and as a result patients were more likely to be sent to hospital.

A high proportion (42.2%) of patients were admitted for multiple reasons, the most common being symptom control and nutritional rehabilitation; symptom control and terminal care; and symptom control, nutritional rehabilitation and respite.

In two cases (3.1%), the Hospice staff felt the admission was inappropriate because of the severity of the child's condition and the need to still continue with cure-directed therapy. These two patients were transferred to hospital after the first day in the Hospice Paediatric Unit.

4.2.4 LENGTH OF ADMISSION

This varied considerably from 1 – 80 days with a median of 14 days and demonstrated quite clearly the open-ended policy of length of admission that Hospice had adopted. Being a pilot project, Hospice was unsure of the duration of admission that may be required by the patients. These figures compare favourably with those from the study done by Stein et al (1989) at Helen House where length of admission was slightly lower but also variable at 8-49 days. A major factor impacting on the length of stay is that alternative placement arrangements have to be made for some patients admitted to the unit. These are patients who had lived with families or in Children's Homes prior to their admission and because of a deterioration in their condition, or lack of skills in the referring Children's Home to care for these children, were unable to be discharged back to the same place. They subsequently needed placement in other Children's Homes resulting in a longer stay for these "social reasons". These factors are unlikely to change and as such one can expect the length of stay to remain variable. Factors prolonging the stay should be identified early to facilitate placement and discharge.

4.2.5 GENERAL MANAGEMENT AND TREATMENT

Few patients required only disease-specific or palliative treatment alone. The majority (76.6%) required both disease-specific and palliative treatment together and there was crossover of treatment. This is in keeping with the literature that some active treatments are the best palliative treatments and that palliative care does not mean withdrawing disease-specific treatment (Hutchinson et al, 2003).

As mentioned there was an increase in the use of ART in patients admitted during the second year of the study (July 2004 – June 2005). This probably correlates with the hospital roll-out of ART which began in April 2004. The data does not include at what stage ART was started, but it was likely to be in the later stages of the disease which can be supported by the multiple pathologies (Table 3-7) the children presented with and the number of children with Category C HIV/AIDS (Table 3-9).

The need for nutritional rehabilitation was equally prevalent in the HIV and non-HIV group with both groups requiring nutritional rehabilitation in a high proportion of patients (46.9%). There are a number of possible factors for this. As children become sicker their ability to eat decreases and they become cachectic and less able to tolerate food. It also takes longer to feed very ill children and if the Children's Home is short-staffed the children may not get the nutrition they require. In addition, the quality of the food may not be the best and poverty which is so rife in southern Africa, will prevent nutrition being optimized.

4.2.6 OUTCOME

Patients were either discharged improved (40.6%) or in the same condition (15%), transferred to hospital because of deterioration (17.2%) or died (21.9%). All 14 of the deaths were expected and this compares to the figures from Burne et al (1984) in their study of Helen House where 8 children (15.4%) died over a one year period.

Patients were transferred to hospital due to a deterioration in their condition when Hospice was unable to cope with more intensive disease specific treatment. In each case the paediatrician was involved in the decision and arranged the transfer to the hospital.

This highlights the importance of collaboration between hospice and hospital which is stressed in the literature (Hain, 2004). The need for co-ordination of services is essential (Doyle, 1998) which will prevent fragmentation of care and the importance of identifying a keyworker to co-ordinate care is emphasized (ACT, 2003; Himelstein et al, 2004). In the situation studied at this hospice, the CHOMP paediatrician formed the vital link between hospice and the hospitals. In addition, the need to transfer patients to hospitals highlighted the problem that Hospice had no permanent and accessible transport especially over weekends. This is a costly but necessary logistical requirement especially as children with HIV can deteriorate very quickly and should be treated aggressively for acute and easily reversible conditions such as pneumonia, diarrhoea and dehydration. This could of course, apply to children without HIV/AIDS.

4.2.7 FOLLOW-UP

Hospice had very little follow-up of the patients compared to CHOMP and the hospital/clinics ie14.9% compared to 66.0% and 97.9%. 45.3% of patients were followed-up by both CHOMP and the hospital. This indicates that Hospice is a point in the care of these patients rather than transference of care. This is supported in the literature (Hain 2002, 2004) that Hospice care has a role in the overall management of the patient and that hospices should not own palliative care but rather advocate an approach to the care of the patient with chronic life limiting illnesses (Corr, 1985). Hospital care remains the main follow-up with patients as well as CHOMP. Hospice is simply part of the continuum of care. Of importance is the collaboration that exists between Hospice and CHOMP.

There is the possibility that a large percentage of children with chronic life-threatening illnesses do not require an in-patient hospice unit or hospital as they are managed as outpatients. When an in-patient hospice based unit is the only point of entry into a palliative care service many of these patients may be missed. Quality of life issues and holistic palliative care may be inadequately addressed in many of these patients at an outpatient level. The concern is that although the figures show that Hospice does not need a large paediatric home care team at this stage, they may be overlooking patients as well as the opportunity to teach caregivers and family members about palliative care both in the Children's Homes and the family homes.

4.3 CONCLUSIONS

The wide range of ages of children admitted and the diversity of illness experienced, supports the literature that staff working in paediatric hospice units need to have a wide base of knowledge about children of differing physical, emotional and developmental stages as well as the spectrum of diseases they are presented with, as these are often complex and rare (Corr, 1985; Goldman, 2001; Horsburgh, 2002). Children admitted to the unit came from both Children's Homes as well as homes of family which is important as families need support and information (Corr, 1985) and paediatric palliative care does not just support the child but the family as well (Gold, 1997). In addition, caregivers from homes need support: they get very little in the line of de-briefing and many of them have formed strong bonds with children they have cared for.

There was a fall off in the number of admissions over the second year of the study. This could be attributed to a number of factors namely:

- many more children are being treated with ARV and therefore the need for admission falls away as the patients are symptomatically better
- lack of advertising, dissemination of information and promotion of the paediatric unit
- the geographical location of the unit in an upmarket area that is far from many lower income areas which are associated with a higher incidence of HIV/AIDS.

The latter point above is stressed in the literature by Doyle (1998), who feels that the palliative service must be easily accessible to families. Contro et al (2002), found that cultural differences prevented good palliative care and Horsburgh et al (2002), stated that lower socioeconomic groups were less likely to use hospice care. Most likely poor accessibility, high transport costs, language and cultural differences are perceived as real barriers. The distance between the referring Children's Homes and Wits Hospice varied between 10-40 km. Relatives living in Soweto would have to catch 2 taxis to get to Wits Hospice thereby significantly increasing the costs for them.

The length of admission was variable but as the unit was never full at any given time there was no pressure to discharge. Judging by the variability of admission length, Hospice will need to adopt a flexible policy of length of admission.

Although HIV/AIDS comprised the largest group of patients, the non-HIV groups were all similarly small. Based on the data one can deduce that TB predicts strongly for HIV in this patient population in South Africa. The presence of malignancy predicted against having HIV in this group of patients although the sample of patients suffering from malignancy was very small. Other infections were common in both groups of patients and were treated rapidly with specific treatments. Neurological problems were common in both groups. Wounds and the need for procedures were uncommon in both groups of patients. Nutritional requirements played an important role in the management of both HIV and non-HIV patients, with 31.1% of all patients requiring additional nutritional care. The patients admitted had complex multiple diagnoses and problems. This means that Hospice staff need a high level of awareness and knowledge of diseases, and need to actively look for complicating factors beyond the primary reason for admission. Due to the frequency of Category C AIDS, presentations of secondary conditions may be atypical. Multiple treatment strategies lead to complex drug interactions and side effect profiles.

Based on these results it is difficult to say that patients with life-limiting illnesses need either disease-specific or palliative treatment alone. HIV patients were the only group to show they were less likely to need palliative treatment alone. The majority of patients needed aspects of both palliative and disease-specific treatment.

As shown, a wide spectrum of outcomes can be expected and in particular the incidence of patients needing transfer to hospital when they require more intensive treatment is 17.2%. This is a source of concern for Witwatersrand Hospice as it does not have a formal transport service and the need for transportation can precipitate an emergency after hours.

From the results, it is clear that follow-up of patients in terms of home care is less of a requirement with children than with adults. Paediatric hospice care is a point in the continuum of care and collaboration is more important. At this stage and based on these results, Hospice need not develop extensive outpatient capacity as there is adequate follow-up by the hospital and CHOMP. However, the point raised above that there are 'hidden' patients at outpatient facilities who require palliative care, is appreciated and as paediatric palliative care develops these patients need to be actively looked for.

Based on the data obtained i.e. patient numbers, the prevalence of the underlying conditions especially HIV, the reason for admission, the extensive treatment, the outcome, and the literature review, the need for paediatric palliative care is clearly demonstrated. However the % bed occupancy and the declining numbers of admissions over the past year indicates that increasing the bed capacity of the unit is not an immediate requirement at present. In addition, the geographical location of the unit is also a major factor. As in the rest of the world, issues of sustainability and regulation of paediatric hospices may be more of an issue (Sheldon et al, 2002).

There is a contrast between first and third world paediatric palliative care mostly because of an increased incidence of HIV/AIDS in the latter.

4.4 RECOMMENDATIONS

The recommendations below are in accordance with Objective 5 as laid out in Chapter 1: to make recommendations for the future development of the Paediatric Palliative Care Unit at Witwatersrand Hospice.

The following are recommendations suggested as a result of this research:

- **Maintaining the unit as a short or long term unit or both**. In terms of length of admission, Hospice will need to look at this financially as it is not cost effective to keep patients admitted for long periods of time.

  They may choose to continue their policy of flexibility with regard to length of admission but it needs to be clearly defined. Respite care, step-down care and care related to procedures could be more rigidly set in terms of number of admission days, whereas symptom control and terminal care may need a more flexible policy, as well as social issues such as placement of children.

  In addition, the considerable social problems facing these children need to be considered in the context of length of admission. One of the conditions for admission for children with associated social problems is that alternative placement arrangements need to have been started in the hospital otherwise Hospice could become a "waiting place" for children with social problems. Given the nature of HIV and the fact that it is a family disease with associated financial problems and a welfare system that is not as good as in developed countries, this could be a major determinant.

- **HIV/AIDS versus other conditions**. The importance of HIV/AIDS as the primary reason for admission will continue until the majority of patients are receiving antiretroviral agents. Based on our figures, without HIV/AIDS at present, we would not be able to justify the need for a designated paediatric unit as the non-HIV group admitted was small (29.7%).

Clearly the needs of the HIV versus the non-HIV group are very different. The HIV group needs more symptom control and less palliative care alone than the non-HIV group. As treatment for HIV and related infections improves, the disease requires more complex and long term management. This chronicity, the high prevalence of TB (53.3% in this group) and other infections, and the need for nutritional care (31.1%) places this group of patients at times too well for traditional inpatient hospital care and yet needing ongoing inpatient care or supervised home-based care. Hospice is in a unique position to answer this need. With their network of community-based nurses, they could train and support parents, siblings and other relatives on the basic nursing care and needs of these patients. Due to the high proportion of patients requiring disease specific treatment, the continued involvement of a paediatrician (through CHOMP) is essential. The question is raised as to the need of a palliative care unit as more patients are actively treated with ARV's and their condition improves? However, as the epidemic matures, Hospice care could be an important option in cases where there are no further treatment options and the disease is progressing. Conditions such as multi-drug resistant (MDR) TB and mycobacterium avium complex (MAC) infections may also be conditions that require ongoing care.

The non-HIV group need more palliative care, respite and terminal care which has been the more traditional role of hospice in the past. Therefore Hospice is more appropriately geared to deal with this, but still needs collaboration with a paediatrician.

The Witwatersrand Hospice Paediatric Unit needs to be able to offer the full spectrum of palliative, disease-specific, respite, terminal and nutritional treatment on a long term basis in order to meet all the needs of the patients requiring admission.

- **Ongoing training and support of staff caring for the children**. Paediatric hospice patients encompass a wide range of illnesses and therefore staff need a wide base of knowledge of all aspects of physical, emotional and developmental paediatrics. This is well supported in the literature (Corr, 1985; Goldman, 2001; Horsburgh, 2002). In addition to the conventional aspects of caring for paediatric patients certain recommendations need specific mention based on the findings of this report.

Both HIV and non-HIV patients require nutritional rehabilitation and it is imperative that all staff members understand all aspects of feeding in these patients. Intensive and ongoing training needs to be undertaken by Hospice to ensure the best possible feeding and nutritional practices are adopted. Consultation with a dietician/nutritionist may be a requirement, and ongoing and regular guidance from a paediatrician is essential.

Infections are common in the entire spectrum of paediatric hospice patients and as a result Hospice staff need to be able to recognize, diagnose and treat infections rapidly and effectively. Regular training is necessary to ensure all staff members have the knowledge of a wide spectrum of infections and their presentation in immunecompromised patients.

Hospice staff need an equally good knowledge of neurological problems in these children and need an understanding of neurological conditions, observations, drugs and complications.

As pointed out in the literature, it is common for staff to suffer from personal stress as a result of working with the children and their families (Overton, 2001). Effective support and supervision are important considerations in the development of Hospice paediatric palliative care.

In addition, caregivers from Children' Homes need support in terms of debriefing and ongoing educational training. Hospice is in an excellent position to broaden their base and offer ongoing support in this regard.

- **Expanding the unit**. There is not enough evidence to recommend an immediate expansion of the paediatric unit in terms of beds and the unit should remain as part of the adult unit for now even though the view has been expressed in the literature that this is not ideal (Hain, 2002; ACT, 2003). The need to develop the capacity of the unit in terms of a more holistic unit is important. The services of for example, a social worker, dietician/nutritionist, nurse trainer, counsellor, paediatrician etc. are important aspects of developing the unit.

  The need for building a palliative unit in Soweto has been identified and improved accessibility for all people is supported in the literature (Doyle, 1998; Contro et al, 2002; Horsburgh et al, 2002).

  The issue of transport of patients to hospital, in particular over weekends needs to be addressed. Possible solutions are the use of designated volunteers or a contract with a private ambulance service.

- **Advertising the unit**. The researcher recommends a programme of advertising, marketing and promoting the paediatric unit to the hospitals as well as the community, in order to improve awareness of the unit and thus improve bed occupancy. This programme should be audited and based on the results the need for a bigger unit will be established.

  As children are coming from both Children's Homes as well as parent's or relative's homes, facilities within the community such as clinics, shopping centres, recreation facilities and churches need to be targeted to advertise and improve possible intake of patients.

Hospital cancer units and other chronic disease units (including out patient clinics) need to be approached and offered good respite facilities and terminal care. Many of those doctors will be doing their own symptom control and may be less enthusiastic to use hospice for symptom control. Some may be concerned that Hospice may not be as "active" as they would like. When HIV units and Children's Homes caring for children infected with HIV are approached they need to be promised good symptom control and standard paediatrically-guided disease specific treatment.

Patients with chronic life-limiting non-HIV diagnoses need to be sought as Hospice is in an excellent position to offer respite, palliative and terminal care to this group of patients.

- **Establishing links.** Hospice needs to establish links and close ties with hospitals and paediatric units in order to develop an ease of referral for those patients requiring transfer to hospital. As mentioned and supported by this report, Hospice is a point in the continuum of care and therefore needs to be able to form part of the multidisciplinary and multiorganisational team caring for these children. These points are well documented in the literature in section 2.5 and 2.8 above. Hospice and CHOMP have developed a wonderful working relationship which highlights the benefits of organizations working together. This collaboration needs to be developed between the hospitals and Hospice. In addition, Hospice and CHOMP need to look at developing a transport system for the transfer of patients to hospitals when their condition deteriorates.

- **Financial viability.** Hospice needs to consider running an audit to cost the unit, especially as there is evidence to support the fact that small units are not cost effective (McQuillan et al, 1996). In addition, the high staff: child ratio required, and the need for longer term admissions (between 1-3 months) will contribute greatly to the expense of the unit.

- **Further research.** This research opens up the scope for further research into the need for paediatric hospice care in particular looking at the psychosocial and socioeconomic aspects of the children admitted, and whether Hospice is answering the needs of patients admitted.

In closing, the researcher would like to draw the reader's attention to the important view, that Hospice is ultimately a philosophy of care and does not refer to a structure or building allowing this care to take place. Hospice care can be practiced anywhere if there is a need and it is the answer to this need by caring individuals that is important.

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APPENDICES

APPENDIX 1

DATA ANALYSIS FORM USED FOR DATA CAPTURING FOR THIS STUDY

DATA ANALYSIS FORM

Hospice number:…… ……………………….. Date of Birth………………………

Hospital number:…………………………….. Age ……………………..

Date of admission:… ………………………. Sex…………………………………

Date of discharge:….. ………………………..

Date of death:……………………………...

Genogram / psychosocial:

Diagnosis:

1) ………………………………………..
2) ………………………………………..
3) ………………………………………..
4) ………………………………………..
5) ………………………………………..
6) ………………………………………..

Reason for admission:

1) step down from hospital……………………………………………………
2) respite from home…………………………………………………………..
3) symptom control……………………………………………………………
4) procedure related……………………………………………………………
5) terminal care………………………………………………………………...
6) nutritional rehabilitation……………………………………………………..

Length of admission: ………………………………………………… days.

General management and treatment:

1) Active treatment
    a. TB treatment……………………………………………………………..
    b. Antiretroviral therapy…………………………………………………….
    c. Antibiotic therapy………………………………………………………..
    d. Chemotherapy……………………………………………………………
    e. Oxygen therapy…………………………………………………………..
    f. Procedures
        i. intravenous therapy…………………………………………………
        ii. blood transfusions…………………………………………………..
        iii. Other………………………………………………………………..
2) Palliative treatment
    a. Pain control………………………………………………………………
    b. Symptom control…………………………………………………………
    c. Psychosocial input………………………………………………………
    d. Spiritual input…………………………………………………………….
3) Nutritional rehabilitation……………………………………………………

Outcome of admission:

1) improvement and discharge to home………………………………………………
2) condition remained the same……………………………………………………….
3) condition deteriorated and the patient was transferred to hospital or acute care facility……………………………………………………………………………………
4) condition deteriorated and the patient died……………………………………..

Follow-up:

1) CHOMP follow-up…………………………………………………………..
2) Hospice home care follow up……………………………………………..
3) Both CHOMP and Hospice follow up……………………………………..
4) Hospital follow-up (clinics)………………………………………………..

APPENDIX 2

COPY OF CONSENT DOCUMENT FILLED OUT BY THE PARENTS OR LEGAL GUARDIANS ON ADMISSION OF CHILD TO WITWATERSRAND HOSPICE.

CONSENT FORM FOR HOSPICE ADMISSION

I, ________________________________ being the parent/legal guardian

of ________________________________ hereby consent to his/her being

admitted to the Houghton Hospice. The reasons for admission have been explained to me and I have received details regarding the location and contact number for the Hospice.

SIGNED:

____

(Parent/Legal guardian)

Date: ________________________________

Contact No.: ____________________

Contact address:

____

Name and signature of referring Doctor: ____________________________

Contact No.: ____________________

APPENDIX 3

COPY OF INFORMED CONSENT FILLED OUT BY PARENTS OR LEGAL GUARDIANS FOR THIS SPECIFIC RESEARCH PROJECT

CONSENT FORM

Witwatersrand Hospice – Paediatric Palliative Care Unit

I hereby confirm that I have been informed by Doctor Danielle Catherine Lincoln, about the nature of the research she is doing. I have received, read and understand the written information sheet regarding the research.

I………………………………………………, the parent / guardian of ……………… ………………………………, hereby give consent for the clinical records of the above-named child to be used for a research project identifying the needs of patients admitted to this unit and their outcome.

Signed: ………………………………………….. Date: ………………….

Witness: ………………………………………….. Date: ………………….

Doctor: ………………………………………….. Date: ………………….

APPENDIX 4

COPY OF INFORMATION SHEET GIVEN TO PARENTS OR LEGAL GUARDIANS ON ADMISSION OF CHILD TO WITWATERSRAND HOSPICE.

INFORMATION SHEET FOR PARENTS / GUARDIANS

WITWATERSRAND HOSPICE – PAEDIATRIC PALLIATIVE CARE UNIT

Your child / guardian has been admitted to the Witwatersrand Hospice Paediatric palliative care unit.

When your child / guardian leaves this unit their records will be required in a special research project which will be performed during 2003 to 2005. Specific information from the notes will be used namely diagnosis, the reason the child was admitted, the length of their admission, the treatment of the child, and the outcome and follow-up of the child.

The name of the child will not be used. No photographs of the child will be used. We require you to sign consent for this information to be used in the study.

APPENDIX 5

LETTER OF AUTHORIZATION FROM WITWATERSRAND HOSPICE.

PO Box 87600 Houghton 2041
50 Second Avenue Houghton Johannesburg
Tel: +27 (0)11 483 9100 Fax: +27 (0)11 728 3104
Email: offices@hospicewitwatersrand.org.za

Hospice
no end
to caring
Hospice Association
of the Witwatersrand

17th March 2005.

TO WHOM IT CONCERNS

- Hospice Association of the Witwatersrand is fully supportive of the research being done by Dr. Danielle Lincoln toward her M. Phil Palliative Medicine.

- Dr. Lincoln is one of our locum doctors and is authorised to have access to our patients and files as needed for her research, within the ethical guidelines.

BARBARA CAMPBEL-KER
EXECUTIVE DIRECTOR

Accredited by the Hospice Palliative Care Association of South Africa
Nonprofit Organisation No.: 000-708 NPO
PBO No.: 930002687

APPENDIX 6

ADMISSION CRITERIA

ADMISSION CRITERIA TO PAEDIATRIC PALLIATIVE CARE UNIT, WITS HOSPICE.

1. GENERAL ADMISSION CRITERIA

Children will be admitted with illness that does not respond to curative treatment such as cancer, HIV/AIDS, other chronic illness (e.g. neurodegenerative/genetic).

We admit for 3 reasons:

a) symptom control
b) respite care
c) terminal care – (where family cannot cope with the dying child)

Age: We will be flexible and individualize children between 12-18 years. Children less than 12 years will be easily accommodated in our Paediatric Ward. Younger children and babies may have their mother's or caregivers accompany them.

Length of stay:

Admissions are short-term, most of them for only a few days up to 2 weeks. Occasionally it may be longer if alternative placement is being sought/social problems etc.

2. OTHER SPECIFIC ADMISSION CRITERIA

a) Chronic diarrhoea that has been initially investigated in hospital or that persists after admission to hospital.

b) Acute pneumonia – generally managed in hospital, but if on oral antibiotics and oxygen therapy only, may be appropriate.

c) PCP pneumonia – managed in hospital initially, but may be transferred for symptom control of dyspnoea (need oxygen) or respite until home oxygen organised.

d) Mild Kwashiorkor/malnutrition.

e) Seizures that have been worked up, but remain an uncontrolled symptom.

f) Severe oral thrush/herpes stomatitis for intensive oral hygiene and nutrition.

g) Chronic Suppurative Otitis Media (CSOM) control – aural hygiene.

h) CongestiveCardiac Failure from Cor Pulmonale

i) Procedures such as blood transfusions, abdominal paracentesis.

j) Psychosocial problems – respite, placement, anxiety, depression

APPENDIX 7

CATEGORIES OF HIV DISEASE (Gauteng Department of Health, 2001)

Appendix A

CDC Criteria For Diagnosing HIV Infection

with modified AIDS defining conditions

Category N: Not symptomatic

Children who have no signs or symptoms considered to be the result of HIV infection or who have only one of the conditions listed in Category A.

Category A: Mildly symptomatic

Children with two or more of the conditions listed below but none of the conditions listed in Categories B and C.

1. Lymphadenopathy ((0.5cm at more than two sites; bilateral – one site)
2. Hepotomegaly
3. Splenomegaly
4. Dermatitis
5. Parotitis
6. Recurrent or persistent upper respiratory infection, sinusitis or otitis media.

Category B: Moderately symptomatic

Children who have symptomatic conditions other than those listed for Category A or C that are attributed to HIV infection. Examples of conditions in clinical Category B include but are not limited to:

1. Anemia (<8 gm/dL), neutropenia (<1,000/mm^3), or thrombocytopaenia (<100,000/mm^3) persisting ≥30 days.
2. Bacterial meningitis, pneumonia or sepsis (single episode).
3. Candidiasis, oropharyngeal (thrush), persisting (>2 months) in children >6 months of age.
4. Cardiomyopathy.
5. Cytomegalovirus infection, with onset before 1 month of age.
6. Diarrhea, recurrent or chronic.
7. Hepatitis.
8. Herpes simplex virus (HSV) stomatitis, recurrent (more than two episodes within 1 year).
9. HSV bronchitis, pneumonitis, or esophagitis with onset before one month of age.
10. Herpes zoster (shingles) involving at least two distinct episodes or more than one dermatome.
11. Leiomyosarcoma
12. Lymphoid interstitial pneumonia (LIP) or pulmonary lymphoid hyperplasia complex.
13. Nephropathy.
14. Nocardiosis.
15. Persistent fever (lasting > 1 month).
16. Toxoplasmosis, onset before 1 month of age.
17. Varicella, disseminated (complicated chickenpox).

Category C: Symptomatic

Children presenting with <u>any</u> of the following (modified) CDC category C conditions will be considered to have AIDS:

- <u>Serious bacterial infections, multiple or recurrent</u> (i.e. any combination of at least 2 culture-confirmed infections within a 2-year period), of the following types: septicaemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media, superficial skin or mucosal abscesses, and indwelling catheter related infections).

- <u>Encephalopathy</u> (at least one of the following progressive findings present for at least 2 months in the absence of a concurrent illness other than HIV infection that could explain the findings):
  a) failure to attain or loss of developmental milestones or loss of intellectual ability;

b) impaired brain growth or acquired microcephaly, demonstrated by head circumference measurements or, if available, CT or MRI;
c) acquired symmetric motor deficit manifested by 2 or more of the following: paresis, pathological reflexes, ataxia, or gait disturbance.

- Pneumocystis carinii pneumonia (PCP) as suspected in young infants (with peak incidence 3-6 months) with severe respiratory distress and hypoxia, and a paucity of auscultatory signs, or in whom induced sputum confirms the presence of the organism

- Wasting syndrome in the absence of a concurrent illness other than HIV infection that could explain the following findings:
  a) persistent weight loss >10% of baseline, OR
  b) downward crossing of at least 2 percentiles on the weight-for-age chart, OR
  c) below 5th percentile on weight-for-height chart on 2 consecutive measurements, more than30 days apart, PLUS i) chronic diarrhoea (i.e. at least 2 loose stools per day for >30 days), OR ii) documented fever for >30 days, intermittent or constant.

- Extrapulmonary or disseminated TB

- Opportunistic infections as documented in the CDC revised classification system for HIV infection in children less than 13 years of age (1994)

- Malignancies: lymphoma, Kaposi's sarcoma

APPENDIX 8

WHO CLINICAL STAGING OF HIV/AIDS FOR INFANTS AND CHILDREN

APPENDICES

Appendix 1: Interim revised WHO clinical staging of HIV/AIDS for infants and children

(For persons aged under 15 years with confirmed laboratory evidence of HIV infection: HIV antibody if aged 18 months and above; virological or p24 antigen testing if aged under 18 months)

Stage I

- Asymptomatic
- Persistent generalised lymphadenopathy

Stage II

- Hepatosplenomegaly
- Papular pruritic eruptions
- Seborrhoeic dermatitis
- Extensive human papilloma virus infection
- Extensive molluscum contagiosum
- Fungal nail infections
- Recurrent oral ulcerations
- Lineal gingival erythema (LGE)
- Angular cheilitis
- Parotid enlargement
- Herpes zoster
- Recurrent or chronic RTIs (otitis media, otorrhoea, sinusitis)

Stage III

- Moderate unexplained malnutrition not adequately responding to standard therapy
- Unexplained persistent diarrhoea (14 days or more)
- Unexplained persistent fever (intermittent or constant, for longer than one month)
- Oral candidiasis (outside neonatal period)
- Oral hairy leukoplakia
- Acute necrotizing ulcerative gingivitis/periodontitis
- Pulmonary TB

- Severe recurrent presumed bacterial pneumonia
- Unexplained anaemia (<8g/dl), and or neutropenia (<500/mm^3) and or thrombocytopenia (<50 000/mm^3) for more than one month
- Chronic HIV-associated lung disease including bronchiectasis
- Symptomatic lymphoid interstitial pneumonitis (LIP)

Stage IV

- Unexplained severe wasting or severe malnutrition not adequately responding to standard therapy
- *Pneumocystis* pneumonia
- Recurrent severe presumed bacterial infections (e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia)
- Chronic herpes simplex infection (orolabial or cutaneous of more than one month's duration)
- Extrapulmonary TB
- Kaposi's sarcoma
- Oesophageal candidiasis
- CNS toxoplasmosis (outside the neonatal period)
- HIV encephalopathy
- CMV infection (CMV retinitis or infection of organs other than liver, spleen or lymph nodes; onset at the age one month or more)
- Extrapulmonary cryptococcosis including meningitis
- Any disseminated endemic mycosis (e.g. extrapulmonary histoplasmosis, coccidiomycosis, penicilliosis)
- Cryptosporidiosis
- Isosporiasis
- Disseminated non-tuberculous mycobacterial infection
- Candida of trachea, bronchi or lungs
- Visceral herpes simplex infection
- Acquired HIV-associated rectal fistula
- Cerebral or B cell non-Hodgkin's lymphoma
- Progressive multifocal leukoencephalopathy (PML)
- HIV-associated cardiomyopathy or HIV-associated nephropathy